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Quality of support services provided to parents of asthmatic children at Bronx Municipal Hospital Center as perceived by mothers and pediatric residents.

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QUALITY OF SUPPORT SERVICES PROVIDED TO PARENTS OF ASTHMATIC CHILDREN AT BRONX MUNICIPAL HOSPITAL CENTER AS PERCEIVED BY MOTHERS AND PEDIATRIC RESIDENTS

A Dissertation Presented

By

NADIA BARBARA JENSEN

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Richard Gillerman has given special encouragement to complete this project. This dissertation is dedicated to him with love and respect.

ABSTRACT

Quality of Support Services Provided to Parents of Asthmatic Children at Bronx Municipal Hospital Center as Perceived by Mothers and Pediatric Residents

(February, 1985)

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Thirty mothers of asthmatic children, ages six to twelve, and thirty-six pediatric resident physicians were interviewed at Jacobi Hospital, Bronx Municipal Hospital Center. Interviews were conducted to determine possible differences in perceptions of quality of service in these areas:

(1) Emotional support for mothers of asthmatic children;

(2) General information about asthma;

(3) Information related to home care of asthmatic children;

(4) Information related to school care of asthmatic children.

The areas outlined above were expanded to include twenty behaviors related to caring for an asthmatic child. The researcher developed questionnaires for mothers and resident pediatricians. Questionnaires were reviewed by a fifteen-member group of health care workers at Jacobi Hospital.

Mothers were asked to rate the pediatrician's skills in giving information and support. Pediatric residents were asked to report how effective they perceived themselves to be in providing these services to parents. Mothers and pediatric residents were also asked to indicate the health care provider who would be the most appropriate person to provide services to parents. Data from these questionnaires were analyzed to determine differences between perceptions of mothers and pediatric residents.

Results suggested that mothers were generally satisfied with the quality of support and information they received from their child's pediatrician. However, the majority of mothers indicated that they would like more information about effects of asthma and medication on their child's school performance. A majority of pediatric residents stated that they were generally effective in providing support and information to mothers. However, residents' excessive work loads and limited knowledge of Spanish adversely affected their ability to provide these services.

Mothers most frequently selected asthma specialists as "ideal providers" of support and information, while the majority of residents stated that a general pediatrician would be the most appropriate health care worker to provide these services.

Finally, results suggested that the majority of pediatric residents at Jacobi Hospital would be interested in receiving training related to communicating with parents of chronically ill children.

Mothers' comments suggested that some teachers might benefit from receiving information about the etiology of asthma and effects of asthma medications on children's school performance.

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CHAPTER I

INTRODUCTION TO THE STUDY

Today's parents often have a variety of relationships with professionals who are involved in the care and education of children. Parents, as they raise their families, meet with and receive information from teachers, physicians, and, in some cases, educational and medical specialists.

The first professional with whom a parent consults is often a pediatrician. This relationship is established at the child's birth and continues through his/her adolescence. Parents rely on pediatricians to provide information, support, and medical care for their children. Parents of children with chronic illnesses often rely even more on their pediatricians to provide these services. For the purpose of this study, relationships between pediatricians and mothers of school-aged asthmatic children were studied.

The major purpose of this study was to discover if there is a need to provide training opportunities to pediatric resident physicians to enable them to improve communication skills with parents of chronically ill children. Results of the study are presented in Chapters I-V.

Chapter I will describe a similar study completed in 1979 at Bronx Municipal Hospital Center, Department of Pediatrics. The problem and significance of the study will be discussed. Information regarding incidence and prevalence of asthma will be included. Questions guiding the study are presented, as well as definitions of terms used in this dissertation.

Chapter II will provide a review of the literature related to this study. Topics included are: Impact of chronic asthma on school-aged children; impact of chronic asthma on parents of school-aged asthmatic children; training programs for pediatricians; recommendations of the Task Force on Pediatric Education; communication training in pediatric residency programs; and self-reports as a research method. Descriptions of similar studies will be included in this chapter.

Chapter III will describe questionnaire development and setting of the study. Procedures followed in data collection will be explained.

Chapter IV will provide discussion of data analysis procedures. Data are presented in tables and discussed.

Chapter V includes a summary of the study and its conclusions. Results are discussed in relation to the five questions guiding the study, as outlined in Chapter I. Implications for further research and training of pediatricians, parents, and teachers are presented.

Background of the Study

In 1979, Stein, Jessop, and Reissman completed a study, entitled "Unmet Health Needs of Chronically Ill Children," at Jacobi Hospital, Bronx Municipal Hospital Center. Mothers of 100 children with a wide range of chronic illnesses, including asthma, were interviewed to determine whether families were receiving services typically needed by chronically ill children and their parents. Percentages of mothers receiving seven specific services are summarized in the following table:

TABLE 1

PERCENTAGES OF MOTHERS RECEIVING SERVICES
FROM HEALTH PROFESSIONALS
(N = 100)

Services	Percentage
Education	78%
Acute Illness Care	90%
Health Care Maintenance	80%
Advice and Future Planning	23%
Support	25%
Genetic Counseling	45%
Coordination of Services	66%

Although three-quarters of respondents stated that they had received information about their child's chronic condition, only one-quarter of mothers interviewed were satisfied with the quality of advice and support provided by their child's physician. Data also indicated that, as a result, mothers frequently seek these services from non-medical providers, especially family and friends. Stein et al. suggested that non-medical providers are not always able to provide accurate information to mothers:

> While friends and family are no doubt the best providers of emotional and social support, questions can be raised as to the adequacy of their knowledge. (p. 8)

Results of work completed by Stein et al. indicated the need for further research regarding the absence of advice and support by professionals in

this setting. For purposes of this study, relationships between resident pediatricians and mothers of school-aged asthmatic children were investigated. Information and support were the specific areas of communication studied.

Incidence and Prevalence of Asthma

Asthma, the most common chronic childhood illness, affects both sexes and all races (Jacoby, 1978). Approximately nine million Americans suffer from the disease. The condition may begin at any age and occasionally develops soon after birth (Chow et al., 1978). Among children ages six to sixteen, the asthma rate is 32 per 1,000 (Castleman et al., 1981). It is estimated that there are 1.2 million school-aged children with asthma in the United States (Chiaramonte et al., 1977). Attacks cease in adolescence in approximately seventy percent of asthmatic children (Gibson, 1972).

Asthma is the leading cause of school absenteeism, accounting for twenty-five percent of all days lost from school (Twarog et al., 1981). Economic impact of the illness is staggering. In 1975, approximately 45,000 children in the United States were hospitalized because of asthma attacks, with an average stay of more than five days at a total estimated cost of more than $35 million (Castleman et al., 1981). A cure for the illness has not yet been found. In many cases, the disease is controlled through the use of medications which must be administered by parents, teachers, and sometimes children themselves.

Statement of the Problem

In their discussion of parent involvement in the care of children with asthma, Chow et al. (1978) write:

> The parent as well as the child requires repeated and comprehensible information about etiologic, clinical, and therapeutic aspects of asthma. Parents need instructions to develop in their child with asthma as increasing responsibility for self-care and to promote the goal of raising the child as normally as possible. (p. 882)

It is important that parents of asthmatic children receive clear and understandable information about their child's illness for two reasons. First, parents must be able to provide adequate home health care. Secondly, the majority of school-aged children with asthma are able to attend classes. Parents are often responsible for providing school nurses and teachers with information about their child's illness and required medications. In addition, pediatricians often perceive parents as being helpful in transmitting medical knowledge in language children will understand (Oremland and Oremland, 1973). This researcher identifies mothers as "information relayers" to both children and school personnel.

The problem guiding this study is that many mothers of asthmatic children do not receive support or information from their child's physician. Without these critical services, it is difficult for mothers to manage their child's illness at home, and to give teachers important information about asthma and asthma medications.

Results of this problem affect all involved. Children's health is frequently jeopardized because they do not receive proper care at home

or in school. Medications may be administered incorrectly or not at all. Teachers do not have the knowledge needed to respond to a student who is suddenly unable to breathe. Parents may be in a similar situation at home. Finally, pediatricians often become frustrated because their patients are not receiving correct dosages of prescribed medications, and are repeatedly admitted to hospitals for emergency treatment.

General Plan of the Study

Certainly there are attending and resident physicians in the Department of Pediatrics at Bronx Municipal Hospital Center who do provide support and information to parents, but data collected by Stein et al. indicated that a large number of mothers are not receiving these important services from their child's physician. This researcher was interested in pursuing results discovered by Stein et al., but chose to alter methodology for several reasons. First, Stein et al. were interested in identifying gaps in health care services provided to parents of chronically ill children. This researcher accepted gaps identified by Stein et al., and designed a study which would identify possible reasons for gaps in service. Secondly, Stein et al. included only mothers in their survey. This researcher chose to have samples of mothers and pediatric resident physicians. This additional component of the methodology was included because the main goal of the study was to determine the need for communication training. In order to achieve this goal, pediatric residents' responses were essential.

A third area in which methodology was altered was in the definition of "General Advice" investigated by Stein et al. In their study, this area of service referred to "advice about the child such as special schools, possible handicaps, behavioral troubles, and things that might be expected later in childhood or adulthood" (p. 3). This researcher included those specific topics in the category of "General Information About the Illness."

Finally, Stein et al. interviewed mothers of children with a variety of chronic illnesses. This researcher chose to limit the study to include only mothers of school-aged asthmatic children. In addition, a separate set of questions related to information about care of asthmatic children in school settings was included in questionnaires.

Thirty mothers and thirty-six pediatric resident physicians were interviewed at Jacobi Hospital, Bronx Municipal Hospital Center. Separate questionnaires were developed for mothers and pediatric residents, and both sets of questionnaires were reviewed by a group of attending physicians, nurse practitioners, and social workers. All interviews were conducted by this researcher. A full description of methodology and data analysis is provided in Chapter III and Chapter IV.

Stein et al. established that many mothers whose children are treated at Jacobi Hospital (1) do not receive advice and support from their child's physician and (2) seek these services from non-medical sources, thereby increasing their chances of receiving incorrect information about their child's illness. The major purpose of this study was to determine the need to provide training programs which would enable

pediatric residents to improve their skills in providing support and information to parents. The following questions guided this study:

1. To what extent do mothers of school-aged asthmatic children treated at Bronx Municipal Hospital Center feel that they receive adequate information and support from their child's physician?

2. To what extent do pediatric resident physicians at Bronx Municipal Hospital Center perceive themselves to be effective in providing information and support to mothers of school-aged asthmatic children?

3. To what extent do mothers of school-aged asthmatic children and pediatric residents agree that pediatricians are the appropriate health care professionals to provide information and support to parents?

4. To what extent do mothers of school-aged asthmatic children feel effective in providing teachers with information about their child's illness?

5. To what extent do pediatric residents at Bronx Medical Hospital Center agree that communication training would improve their skills in providing information and support to parents of children with asthma?

Significance of the Study

Relationships between parents and pediatricians exist for the benefit of children's physical and emotional well-being. The broad purpose of this study was to work toward enabling parents and pediatricians to work together more effectively in caring for chronically ill children.

In addition to being able to diagnose and treat children's asthma, pediatricians must also be able to provide parents with comprehensible information about the illness. Stein et al. determined that many mothers of chronically ill children treated at Bronx Municipal Hospital Center do not receive advice and support from health care professionals. The primary significance of this study is that it has uncovered reasons

why parents are not receiving these services from pediatricians, and why many parents must seek advice and support from non-medical sources.

Results of this study indicated that many pediatric residents agree that their communication skills could be improved through further training. In addition, results also determined that many teachers, because they often know so little about asthma, may benefit from information about the illness and how to provide care in classroom settings if a child suffers an asthmatic attack.

The researcher observed in many instances that pediatric residents seemed to learn about specific communication skills in the process of completing the interview. The possibility that physicians' skills may have been improved in the interview process adds to the significance of the study.

Delimitations of the Study

1. Residents who participated in the study are from only one urban medical center in the United States. Consequently, a regional rather than a national sample was used in the study.

2. Mothers who participated in the study are also from only one urban center in the United States. Again, a regional rather than a national sample was involved in the study.

3. Responses of both populations interviewed do not represent pediatric residents or mothers as a whole. Conclusions from the data must be limited to mothers and pediatric residents who participated in the study.

4. Pediatricians are not identified by this researcher as the only persons responsible for ensuring that parents receive clear information about their child's illness. Parents, whenever possible, must be encouraged to assume responsibility for asking questions and seeking clarification of information being discussed.

5. Self-reports were used to obtain information about pediatric residents' skills in providing mothers with information and support. The researcher is assuming that participants (1) had sufficient self knowledge to complete self-reports and (2) were truthful in their responses.

6. Mothers were asked to rate physician's skills in providing information and support. This researcher is assuming that participants were truthful in their responses.

7. A study of communication among persons or groups requires consideration of verbal, non-verbal, intended, and unintended behaviors. For the purpose of this study, only intended verbal behaviors related to parent-pediatrician relationships were measured.

The possibility of researcher bias could not be controlled in the design of the study. In addition, the researcher did not attempt to control exchange of information about the study among first-, second-, and third-year pediatric residents.

Definitions Used in the Study

Information and support were the two areas of communication investigated in this report. In the context of this study, these terms are broadly defined as follows:

1. Information: Pediatrician talked about the possible causes of the illness; discussed how long the illness might last; explained how medications work and how to give them; answered questions about the illness; provided mother with written materials about the illness in English or Spanish; talked with the mother about how the illness affects the child in school; discussed ways that illness or medications might affect behavior or general school performance.

2. Support: Pediatrician encouraged mother to call him/her with questions or concerns; reassured mother when she became upset about having to care for a chronically ill child; helped mother identify others (family, friends) who can provide support and help; recognized that caring for a child with a chronic illness may have emotional, social, and economic impacts on a mother.

(Please note: "Information" and "Support" were defined more specifically in the list of twenty behaviors described in Chapter III.)

3. Mothers: Throughout the remainder of this study, mothers of asthmatic children, ages five to twelve years, are referred to as "Mothers."

4. Residents: Throughout the remainder of this study, pediatric resident physicians who are completing graduate training programs at Bronx Municipal Hospital Center, Department of Pediatrics, are referred to as "Residents."

CHAPTER II

REVIEW OF THE LITERATURE

A review of the literature related to this study is presented in this chapter. After an introduction, the following topics will be discussed:

(1) Impact of chronic asthma on school-aged asthmatic children;

(2) Impact of chronic asthma on parents of school-aged asthmatic children;

(3) Training programs for pediatricians: recommendations of the Task Force on Pediatric Education;

(4) Communication training in pediatric residency programs;

(5) Self-reports as a research method.

Introduction: The Health of American Children

In the 1979 edition of Healthy People, the United States Surgeon General states:

> The health of American children is better than ever before. The child mortality rate is now far below what it was in 1900 when 870 out of every 100,000 children ages one to 14 died annually. Then, the principal causes of death were infectious diseases--and, although they still are responsible for some illness and death, their threat has been greatly reduced through improved sanitation, nutrition, and housing, as well as use of vaccines and antibiotics. (p. 33)

Child mortality rates, listed in Table 2, have continued to decline significantly since 1900. Decreases in rates are attributed to advances in public health and pediatric research.

TABLE 2

CHILD MORTALITY RATES, 1900-1977

Year	Number of Deaths Per 100,000 Children, Ages 1-14
1900	870
1925	330
1950	90
1977	43

Despite this encouraging report, children from low socioeconomic families continue to have serious health problems related to poverty (Mare, 1982). Black American children have a thirty percent higher mortality rate than white children (Healthy People, 1979). Incidence of low birth weight, congenital defects, child abuse and neglect, lead poisoning, hearing and visual disorders are significantly higher among poor children (Keniston, 1978).

Chronic illnesses, including asthma, are more common among children from low income families (Starfield, 1982). Effects of this illness on children and mothers, as well as how pediatricians are trained to provide health care, are studied in this chapter.

Impact of Chronic Asthma on School-Aged Children

Asthma, the most common childhood chronic illness, affects approximately 1.2 million school-aged children in the United States

(Chiaramonte et al., 1977). A multi-causal etiology including hereditary, infectious, allergic, physical, and psychological factors is now generally accepted by health care providers (Mattson, 1975). Asthma is defined as "an organically based disease process which is probably genetically linked, and which can be triggered by infectious, allergic, or emotional triggers" (Kapotes, 1977, p. 5).

The exact cause of the illness has not yet been determined (Kuzemko, 1980), although a typical attack is easy to recognize (Konig, 1981). Symptoms may include coughing, wheezing, dypsnea, severe chest congestion, and chronic throat congestion (Keslin, 1979). During an asthma attack, bronchial tubes narrow, tissues in the tubes become swollen, and mucus "clogs" form (Smith, 1978).

There are two basic types of asthma, allergic and idiosyncratic (Castleman et al., 1981). Allergic asthma is:

1. Often associated with a personal or family history of allergy or eczema.
2. Often seasonal, with attacks increasing in spring and fall.
3. Typically produced by common allergens and irritants: dust, mold, animal hair, cigarette smoke, and certain foods, such as milk or citrus fruits.

Idiosyncratic asthma is:

1. Not associated with a history of allergy or eczema.
2. May be triggered by any of the following: colds, respiratory infections, aspirin, yellow food dye (tartrazine), urban air, smoke, chemical fumes, or changes in the weather. (pp. 44-45)

Diagnosis of the illness is made easily in most children (Nelson, 1983). Children who have recurrent episodes of coughing and wheezing

are likely to be asthmatic. Diagnosis can be clinically determined by pulmonary function testing (Isselbacher, 1980).

The mildest form of asthma includes infrequent episodes of slight wheezing or congestion. Children with these symptoms do not require medications or hospitalizations for their asthma. Parents may be advised by pediatricians to control environmental or diet factors which seem to cause attacks. The majority of asthmatic children have only occasional episodes which seem to pass quickly.

Other children may suffer from chronic asthma. These children have frequent attacks and must take medications on a regular basis to prevent and control asthmatic episodes. In some cases, children may need emergency treatment and are hospitalized if attacks continue. Most children with moderate chronic asthma are symptom-free by age twenty (Gibson, 1972).

The most severe form of the illness is status asthmaticus, which is "a continuous asthma going on for a long time, such as for more than 24 hours, terminating in exhaustion or sometimes death" (Gibson, 1972). Patients with this acute form of asthma have great difficulty breathing and may require assisted ventilation in an intensive care unit (Brimblecomb and Barltrop, 1978). Children with status asthmaticus must take medications on a regular basis, are frequently hospitalized, and may become homebound and unable to attend school (Williams, 1976).

The mortality of asthma is low. Approximately 2,000 deaths per year occur because of asthma, and the majority of these fatalities are children with status asthmaticus (Keslin, 1979).

The illness may have devastating physical and emotional effects on children. For purposes of this study, effects on school-aged children are discussed.

Physical effects are often related to medications taken to prevent or control attacks. As stated previously, the majority of asthmatic children have a mild form of the illness and do not require medications or regular health care. Approximately 90% of the children who do receive ongoing treatment for their asthma require some form of prophylactic drug therapy (Keslin, 1979).

There are currently more than eighty different brand name drugs for medications used to prevent and control asthma, all of which expand the bronchial tubes. These bronchodilators may be taken by mouth, injected, or inhaled. The most commonly prescribed bronchodilator is Theophylline, which is a non-steroid drug. Theophylline is chemically related to caffeine and has many of the same side effects. Children who take Theophylline often experience nausea, vomiting, gastrointestinal distress, headaches, restlessness, and irritability. These side effects have been observed at "therapeutic dosage levels" in a significant number of asthmatic children (Furukawa, 1984). The most commonly observed effects of Theophylline on children's behavior include increased hyperactivity, shortened attention span, and general lack of concentration (Wassen, 1981). More toxic side effects of the drug include cardiac stimulation and convulsions when taken in large doses (Isselbacher, 1980). The majority of children who require preventive medications for asthma receive Theophylline.

A small number of children do not respond to prophylactic treatment and must receive oral corticosteroids, such as Prednisone, to control their attacks (Evans, 1981). Side effects of steroid drugs have been observed in a significant number of children who receive medications for chronic asthma (Furukawa, 1984). Possible side effects of steroids include cataracts, metabollic disorders, and increased susceptibility to infections (Mascia, 1973). Steroid products may also cause growth suppression in children (Smith, 1978). Although there is great controversy among physicians regarding the use of steroids to treat asthma, a significant number of pediatricians recommend short-term use of these drugs to control severe episodes of chronic asthma (Falliers, 1981).

The ideal management outcome is prevention of all asthmatic episodes. This, unfortunately, is not possible in all cases, and many children require emergency treatment when they suffer an acute attack.

Emergency treatment usually consists of oxygen administered by mask, and one or two shots of adrenalin at twenty-minute intervals. Patients who require emergency treatment for an acute attack often present with the following symptoms:

> Shortness of breath may be so severe that the child has difficulty walking or even talking. The patient may assume a hunched-over, tripod-like sitting position which makes it easier to breath. . . . Abdominal pain is common, particularly in young children. . . . The liver and spleen may be palpable because of hyperinflation of the lungs. Vomiting is not uncommon and may be followed by temporary relief of symptoms. During a severe attack, respiratory effort may be great and the child may sweat profusely; a low-grade fever may develop simply from the enormous work of breathing; fatigue may become severe. (Nelson, 1983, p. 541)

Patients are usually discharged from the emergency room once the attack has subsided, although some children must be hospitalized after severe episodes.

Chronic asthma frequently has serious emotional effects on children. The illness often imposes restrictions on children's physical activities at home and in school (Kapotes, 1977). Asthmatic episodes are extremely frightening to children. During an attack, a child is often conscious but unable to breathe. A "vicious cycle of attack-anxiety-increased severity of attack increased anxiety" is observed in many children with chronic asthma (Castleman et al., 1981).

Feelings expressed by asthmatic children include guilt, anger, fear, envy, sadness, and frustration (Purcell, 1975). Literature on "personality structures" of asthmatic children suggest that children who suffer from this illness are anxious, fearful, aggressive, dependent, and frustrated (Burton, 1968). Alexander (1972) reports that a common emotional problem in asthmatic children is fear of separation from the mother.

Children with any chronic disorder tend to show higher prevalence of adjustment problems than a random group of children without chronic health problems (Mattsson, 1975). It becomes difficult to determine whether emotional problems in chronically ill children are caused or perpetuated by the illness (Kapotes, 1977). Psychiatric consultations for children and parents are necessary in cases where occasional problems persist (Mattsson, 1975; and Smith, 1978).

Pediatricians, psychologists, and psychiatrists seem to agree that chronic asthma may have serious effects on children's emotions and

behavior at home and in school. Physical effects of medications, such as Theophylline, have been shown to increase hyperactivity and reduce ability to concentrate (Furukawa, 1984). As a result, children's school performance may deteriorate. Many children are not able to participate in gym classes or recess activities because exercise sometimes triggers asthmatic episodes (Travis, 1976). Attendance at school is often interrupted because of emergency hospital visits (Mascia, 1973). Many children who are frequently hospitalized because of asthma become shy and withdrawn as a result of separation from their families and peers (Travis, 1976). Painful medical procedures experienced by asthmatic children during hospital treatments may cause fear, anxiety, and anger.

No two children are alike in how they are affected by their asthma. The severity of the illness, parents' reactions to the condition, physical restrictions placed on the child in home and school environments, side effects of medications, frequency of school absence and hospitalizations, and quality of medical care are identified as major factors influencing the extent to which an asthmatic child is affected by his or her chronic condition (Travis, 1976).

Impact of Chronic Asthma on Parents of School-Aged Asthmatic Children

Chronic asthma often has significant social, emotional, and economic impact on asthmatic children and their families (Freudenberg, 1980). In most families, it is the mother who assumes responsibility for care of the asthmatic child, regardless of presence or absence of the father (Travis, 1976).

The severity of the child's asthma directly influences how the mother is affected by the illness. Mothers whose children have mild, infrequent asthmatic episodes and who do not require prophylactic treatments are least affected by their child's chronic condition. This discussion will focus on mothers whose children require special diet and environmental restrictions, receive regular preventive medications and health care, and are frequently hospitalized for emergency treatment.

Management of the illness is typically the mother's responsibility. She must administer medications, take care of the child during asthma attacks, decide when to bring the child to the emergency room, and remain with the child during medical treatments. Mothers are also responsible for removing possible allergens in the home which might cause attacks. In short, the mother often becomes the expert in the care of the child (Kodadek, 1980).

Frequent trips to the doctor or hospital cause disruption of the mother's work schedule if she is employed outside the home. In addition, the mother often struggles to find a balance between providing adequate care for the asthmatic child, and giving sufficient attention to other members of her family.

Burton (1975) reports that many parents of chronically ill children blame themselves for their child's health problems. Mattsson (1975) states that a significant number of parents of children with asthma have feelings of helplessness, fear, irritation, self-blame, and resentment toward the child. Specific problems identified by parents of asthmatic children include having fears about how to manage attacks at home, and

fears about long- and short-term effects of drugs on their child's behavior and general health (Castleman et al., 1981).

Results of other studies also suggest that mothers of chronically ill children have special needs which are usually not met by health professionals. Stein et al. (1979) report that a majority of mothers of children with chronic conditions do not receive advice and support about how to care for their child. Participants in this study indicated that they would like more information about how to manage their child's illness at home.

Three-hundred parents participated in a four-year Asthma Self-Management Project at Columbia University College of Physicians and Surgeons. Results of a needs assessment completed by participants indicated that a majority of parents felt isolated and unsupported, and had significant problems dealing with their child's asthma. Their problems included:

1. Difficulties preventing attacks caused by environmental conditions, such as lack of heat and hot water.
2. Difficulties deciding which steps to take to manage attacks at home.
3. Difficulties discussing asthma with health workers and school officials.
4. Fears about long- and short-term effects and addiction potentials of medications prescribed for their children. (Castleman et al., 1981, p. 45)

Parents in this study identified a variety of problems related to management of asthma in school settings (Freudenberg, 1980). These included:

1. Problems in administration of medications and side effects from asthma drugs.

2. How to handle asthma symptoms in school.

3. How to decide when to keep the child home from school. (p. 524)

Freudenberg states that problems related to school management of asthma are often caused by poor parent-teacher communication. Parents are usually the "primary information link between the medical care system and the school year" (p. 525). In most situations, pediatricians and classroom teachers have no direct contact, and rely on mothers to provide information about their child. Mothers are responsible for giving teachers information about their child's asthmatic condition, how to administer medications, side effects of drugs which may cause behavioral changes, and possible physical limitations caused by the illness. If the mother misinterprets information given to her by the pediatrician, or is not given information at all, it is likely that she will transmit incorrect information to the teacher.

Freudenberg states that health care professionals can help mothers become more competent in providing accurate medical information to teachers by (1) giving mothers clear, understandable instructions regarding school management of the illness, and (2) preparing written materials for classroom teachers about asthma, medications, possible behavioral changes caused by medications, and physical restrictions for sports activities . Mascia (1973) also states that parents must receive information about management of the illness at home and in school in order to reduce the frequency of a child's asthma attacks and hospitalizations.

Providing adequate health services to children and parents is more difficult when the family is poor (Mare, 1982). Mothers may not be able to adapt their home environment to the child's medical needs. For example, a mother may live in an apartment which is too cold and causes her child to suffer acute asthmatic attacks, yet the landlord refuses to turn the heat up.

In addition to housing problems, medical coverage in low-income areas is often inadequate (Mascia, 1973). Although poor children have access to medical services through publicly funded health programs, the quality of care they receive in municipal clinics and hospitals is often of questionable quality. Mothers and sick children are often seen by a different provider each time they visit a clinic or hospital. Non-English speaking mothers have difficulty understanding physicians' or nurses' instructions, and often become too intimidated to ask questions about their child's medical problems (Keniston, 1978). It is often these mothers who, because they cannot communicate with health workers or cannot afford adequate housing for their families, will continue to bring their children to municipal emergency rooms for treatment of acute asthma attacks.

Training Programs for Pediatricians: Recommendations of the Task Force on Pediatric Education

This section includes a brief description of how men and women in the United States are currently trained to become pediatricians. The discussion will focus on recommendations made by the Task Force on Pediatric Education for planning comprehensive pediatric training programs.

Undergraduate Medical Education

Undergraduate medical education generally requires two years of coursework in the basic sciences, followed by two years of required clinical experiences in surgery, obstetrics and gynecology, pediatrics, psychiatry, and neurology. Electives may be completed in specialized areas of these fields.

Students must choose an area of specialty by the beginning of the fourth year of medical school. Applications to residency training programs are completed during the first part of the fourth year.

Between 1965 and 1975, the number of accredited medical schools in the United States increased from 88 to 116; the number of graduates rose from 7,574 to 13,307 per year (Etzell, 1977). There are currently 127 medical schools in the United States (AAMC Directory of American Medical Education, 1983-84). Although there has been a significant rise in the number of physicians trained each year in this country, a serious shortage of doctors exists in rural areas and inner cities. Chicago is an example of a major city with a serious physician shortage:

> Chicago's South Side and other poverty areas in the city have a ratio of 26 physicians for every 100,000 persons, while affluent areas of the city have 210 physicians per 100,000, a variation of more than 800%. Thousands of rural communities in this country lack even the doctor and do not have any system of transportation to medical care elsewhere. (Keniston, 1978, p. 158)

The quality of medical care in the United States is directly related to the quality of education physicians receive in medical school and graduate training programs (Weed, 1976). Jucovy (1981) describes the major problems in medical school curricula:

> Currently, not only is the curriculum fragmented, but also the raw materials of instruction are constituted of perpetually outdated texts, lists, acronyms, mnemonics, flow charts, barely legible hospital notes, and journal articles spawned by career pressures rather than worth. (p. 32)

Weed states that a major problem with current medical education is an overemphasis on knowledge and an underemphasis on caring for patients, showing compassion, and communicating effectively with patients and their families. Maddison (1978) also reports that one of the most serious flaws in medical education is the lack of emphasis placed on "the importance of an attitude of caring, both in medical students and medical graduates" (p. 102).

A substantial number of medical school graduates themselves have stated dissatisfaction with the quality of their undergraduate training and criticize the pressure to memorize facts rather than acquire patient care skills. Graduates interviewed by Lyden et al. (1968) expressed desire for more training and supervised experiences in the psychosomatic aspects of medicine and more contact with patients. Weed (1976) suggests that medical students learn, in addition to facts about disease, how to communicate with patients from a variety of socioeconomic backgrounds. Simpson (1972) suggests that the system of educating physicians be reformed so that medical school graduates are competent, knowledgeable professionals who can communicate effectively with their patients.

Evolution of Pediatric Training Programs

In 1981-82, there were 18,535 open positions for first-year residents in the United States. Of these openings, 1,175 were filled by medical school graduates who wished to become pediatricians. There are

approximately 245 accredited pediatric residency programs in the United States, all of which take three years to complete (1982-83 Directory of Residency Training Programs).

Pediatrics did not emerge as a special area of health care until the early part of the twentieth century (Cross, 1982). The initial focus of pediatrics was on "the particular vulnerability of children to hostile factors in the biological and social environment. . . . At that time, the most obvious environmental risks were contaminated water and milk and crowded and unsanitary living conditions" (p. 31).

The first pediatric residency programs were hospitals based and focused on the prevention and control of infectious diseases. The American Academy of Pediatrics was established in 1930, with the goal of "the attainment of all children of the Americas of their full potential for physical, emotional, and social health" (Cross, 1982, p. 32).

It was not until the mid-1950s that pediatric residency programs began to give equal attention to biological, economic, social, and psychological factors which influence children's health and parents' ability to take care of their children. Although a few pediatric departments developed programs in social and behavioral pediatrics (Deisher, 1973), most programs continued to emphasize biomedical prevention and control of disease. It was not until the late 1960s and early 1970s that pediatric graduate programs began to train pediatricians to deal with behavioral, developmental, and social aspects of child health. Many of these programs have been developed based on recommendations made by the Task Force on Pediatric Education.

The Task Force on Pediatric Education: Its Formation and Recommendations

The Task Force on Pediatric Education was formed in 1976 with the intention of improving child health care in the United States through educational reforms in pediatric training programs. All information presented in this section of Chapter II is a summary of the 1978 report of the Task Force.

In 1976, members of ten major pediatric societies began to meet on a monthly basis to discuss the future of pediatric education. These ten societies included the American Board of Pediatrics, American Academy of Pediatrics, Society for Adolescent Medicine, Society for Pediatric Research, Ambulatory Pediatric Association, American Pediatric Society, Association of Medical School Pediatric Department Chairmen, American Medical Association Residency Review Committee, Society of Professors of Child Psychiatry, and American Academy of Child Psychiatry. Members of these organizations worked together for two years to identify problems in children's health, and to plan educational strategies which program directors are encouraged, but not forced, to implement. Members of the Task Force agreed that problems in the quality of health care can be solved only through implementing changes in pediatric training programs.

The Task Force identified the following major problems which affect the quality of health care for children and adolescents:

- Biosocial and developmental problems, such as early family adjustment difficulties and school failure, adversely affect the health of many children and adolescents. These problems are serious and very wide-spread. All pediatricians should have the skills to cope with them.

- The health needs of adolescents are being inadequately met. Pediatrics should now take upon itself the full responsibility for improving health care and research for this segment of the American population.

- The care provided to children with chronic handicapping conditions continues to be grossly inadequate. Although pediatricians are uniquely qualified to provide this care, too many residency programs underemphasize this aspect of pediatrics.

- Pediatric practice is essentially office-based primary care, while pediatric education often centers around inpatient tertiary care experiences. There needs to be continued, albeit increased, emphasis given to excellent ambulatory care experiences during the pediatric residency.

- Pediatric education is largely financed by revenues generated from hospital inpatient care. It is difficult to obtain adequate financial support for the education of residents in ambulatory settings. An increased understanding of this problem and major revisions of reimbursement formulas are urgently required.

- Fee-for-service reimbursement policies currently encourage pediatricians to treat as many patients per day as possible and discourage the time-consuming counseling essential in effective diagnosis and treatment of biosocial and developmental problems. To meet these needs, pediatricians must spend more time with fewer patients. Fair reimbursement mechanisms for time spent, not for numbers seen, must be developed now. (p. ix)

Members of the Task Force presented recommendations for pediatric training programs in their 1978 report, The Future of Pediatric Training. This report contains specific recommendations for educational reforms which will alleviate some of the problems listed above.

The 1978 report of the Task Force suggests that training programs be designed so that pediatricians are taught to deal with health problems caused by poverty, changing family structures, and other social and psychological factors influencing children's health (p. 1). Task Force members identified the following seven areas of pediatric education

which are often underemphasized in training programs:

a. Biosocial and Developmental Aspects of Medicine: The Task Force suggests that pediatricians be trained to identify and deal with health problems caused or complicated by social and environmental factors. In addition, pediatricians should be trained to help children and their parents cope with problems such as death, suicide attempts, child abuse and neglect, separation, divorce, and birth of a defective child. Pediatricians should become knowledgeable about developmental stages of healthy children, and should also learn more about effects of illness and hospitalization on children and families. In short, the training of pediatricians, according to the Task Force, can no longer focus on providing medical treatment to acutely ill children. Parents are relying more on pediatricians to help them with special problems, especially behavioral disorders and school failure.

b. Adolescent Medicine: Pediatricians are now the primary health care providers for one-quarter of all adolescents, and this number is increasing annually. It is estimated that over 40 million Americans between the ages of 10 and 21 years have untreated health problems for which they do not receive continuous medical care (Millar, 1972). Pediatricians need to be able to provide medical, educational, and counseling services needed by adolescent patients. In addition to basic clinical services, teenagers need information about reproductive physiology, peer relationships, family conflicts, sexuality and birth control, substance abuse, environmental safety, and nutrition. Pediatricians should learn how to establish rapport and trust with adolescents, and should have opportunities to work with teens in both

in-patient and ambulatory care settings.

c. Clinical Pharmacology and Toxicology: Pediatricians need to know the risks, side effects, and complications of all prescribed medications. In addition, it is critical that pediatricians be able to explain to parents and children how to take medications, and how to recognize and respond to possible medical complications caused by drugs. The Task Force also suggests that pediatricians be able to educate parents about poison prevention, especially parents of young children.

d. Community Pediatrics: The Task Force recommends that pediatricians become knowledgeable about community resources which provide educational and social services to children, such as schools, special education programs for physically handicapped and developmentally disabled children, day care centers, and foster care programs. Pediatricians are also encouraged to become more involved in children's advocacy programs to prevent child abuse and neglect, child sexual assault, and to learn more about legislative processes which affect the health, education, and welfare of all children.

e. Health Maintenance: Pediatricians need to recognize nutritional, environmental, and familial factors which directly affect the health of children. The Task Force suggests that pediatricians be trained to counsel parents about their children's behavioral disorders at home and in school. Pediatricians need to become more familiar with community programs, such as screening clinics for early detection of learning disabilities, which provide preventive services to children and parents. In addition, pediatricians should talk with parents about prevention of accidents in the home.

f. Medical Ethics: The Task Force recognizes the difficulty of teaching physicians to "become ethical," and suggests that training programs provide regular opportunities for residents to discuss ethical issues in journal clubs, conferences, and seminars. Discussions about confidentiality, abortion, life-extending technology, and other important ethical issues related to physician-patient relationships should be promoted in residency training programs.

g. Handicapping Conditions and Chronic Illness: The Task Force reports that management of children with long-term health care needs due to chronic and/or handicapping conditions has become an integral part of child health care. In many cases, the role of the pediatrician is to coordinate medical, social, psychological, and educational services provided to children and parents. In addition, pediatricians must be trained to recognize economic, social, and emotional impacts of chronicity on children and their families. Pediatricians should be trained to provide support and counseling services to parents. The Task Force also recommends that pediatricians become competent in providing explanations about illnesses, treatment options, proper use of medications, and possible side effects of drugs:

> Residents should be able to explain to the child and the family the nature and prognosis of the particular disease. They should discuss openly and frankly any questions raised by the patient, even if these concern the possibility of death. (p. 25)

In addition, the report suggests that pediatricians receive training in helping parents deal with school problems caused by the child's illness. (Specific details of how to plan training related to this suggestion are not included in the Task Force report.)

Other recommendations made by members of the Task Force include the suggestion that pediatric training programs provide opportunities for residents to work in both inpatient and ambulatory settings with patients from different socioeconomic backgrounds. Residents should have opportunities to provide continuous care to specific children and parents, especially children with chronic illnesses, in different health care settings. In all training programs, pediatricians should have opportunities to work collaboratively with other pediatricians, pediatric subspecialists, family practitioners, and child psychiatrists.

The Task Force also recommends that pediatricians have opportunities to explore their own and others' feelings when dealing with dying patients and their families. Residents should learn how to make difficult decisions regarding life-support procedures, and how to discuss medical decisions with families.

Members of the Task Force worked on ideas contained in The Future of Pediatric Education from January, 1976 through February, 1978. The final report was presented in 1978 to members of the ten component societies and directors of residency training programs for possible implementation.

Summary of the Task Force Report

The goal of a three-year pediatric residency program is to train pediatricians to provide high-quality health services to children, adolescents, and parents from a variety of racial, cultural, and economic backgrounds. The Task Force states that pediatric residents should learn how to manage long- and short-term health care, and should

eventually be able to serve as teachers and consultants to medical students and resident physicians in pediatric training settings. Residency programs must provide experiences which will enable pediatricians to adequately meet trends in health needs of children and adolescents. Task Force members recognize that factors such as funding, staffing shortages and requirements, practice systems, and distribution of health care workers in different communities will determine how easily directors can implement recommendations in individual residency training programs. Ideas presented in The Future of Pediatric Education are likely to be costly and difficult to implement. However, members state that the important question "is not 'Can we afford to do these things?', but rather 'Can we afford not to do them?'" (p. ix).

Communication Training in Pediatric Residency Programs

> Certainly, the fastest and cheapest way to increase both human and material resources in health and social services is to make better use of what already exists. It costs nothing to try harder to communicate with another person; but it is just such communication that often makes the difference between effective and ineffective health care. (Peitchinis, 1976, p. 1)

The need for parents to receive information and support about their child's asthmatic condition has been discussed in the second section of this chapter. The introduction to this section includes a discussion of common problems in patient-physician relationships. Descriptions of three communication training programs for pediatric residents are presented.

Introduction

Although medical care in the United States has achieved a high level of technical competence, relationships between patients and physicians are often less than adequate (Werner et al., 1979). Systematic surveys indicate that there is "widespread dissatisfaction" among patients regarding the quality of care they receive from their physicians (Korsch and Negrete, 1972). Harry Gordon, Professor Emeritus of Pediatrics and medical consultant to the Patient Relations Office at the Jacobi Hospital, reported that patients and their families have often complained to him about "the failure of doctors to communicate with them, to treat them with respect, to reach out to them as people entitled to know what is happening to them, to care about them" (1979, p. 1).

More than one-third of the malpractice suits in the United States are the result of poor communication between physicians and patients (Wolraich and Reiter, 1979). Poor communication often results in patients not following their physician's advice and not being able to talk about their real concerns (Armstrong, 1979). Common problems in patient-physician communication include patients receiving too much information, too little information, or conflicting information from different sources (Johnson, 1980). Korsch, Gozzi, and Francis (1968) noted through their study of doctor-patient interactions and patient satisfaction that many parents demonstrated "intense concern with and need for information and explanation of their child's disease and what caused it" (p. 861). Interviews with hospitalized patients (Skipper, 1965) revealed that "almost two out of three patients (65%) considered

a 'good explanation' of illness to be one of the most important qualities of a 'good doctor'" (p. 62).

Problems related to physician-patient communication may be caused by inadequacies in the system of medical education:

> Medical schools do an admirable job of teaching their students the complexities of medical science, but they still leave the learning of the "art" of medical practice to the individual's own initiative and intuition. This remains, in our view, a serious omission. However well informed a physician may be, and however conscientious about applying his knowledge, if he cannot get his message across to his patient, his competence is not going to be helpful. (Korsch and Negrete, 1972, p. 66)

Results of studies related to patient-physician communication (Hess, 1969; Helfer, 1970; Helfer and Hess, 1970; Korsch and Negrete, 1972; Warner et al., 1979) indicated that there was a need for medical educators to teach communication skills. These findings were reinforced by recommendations made by members of the Task Force for Pediatric Education in their 1978 report to medical educators.

Most medical schools in the United States began teaching communication courses during the last decade (Best and Samph, 1980; Carroll and Monroe, 1979; Knox et al., 1979). A variety of teaching methods have been used, including audio and video recording, role-playing, and observations of films and experienced interviewers (Pacoe et al., 1976). The majority of these courses, however, are usually limited to learning interviewing skills (Wolraich and Reiter, 1979). Students are taught to obtain information from patients (Coombs and Vincent, 1971). Other factors related to communication, such as listening skills, verbal and non-verbal behaviors (Zakus, et al., 1976), and intended and non-intended messages (Peitchinis, 1976) are generally not studied in

communication courses. Students are rarely taught how to give information to patients at any point in medical school or residency training programs (Wolraich and Reiter, 1979; Werner et al., 1979). Another flaw with communication courses is that they are typically taught only during the first and second year in medical school when students have little or no contact with patients. The majority of students who enter pediatric residencies do not receive further communication training in graduate programs (Werner et al., 1979).

Pediatricians need to be able to obtain a medical history, convey information about illness and treatment, reassure parents, and monitor how well families adapt to problems caused by a child's medical problems (Sanson-Fisher and Maguire, 1980). Pediatricians' communication skills may have effects on parents' ability to prevent and manage their child's health problems. The pediatrician should consider several factors when providing information to parents (Verwoerdt, 1966). These include:

1. What are the parent's emotional and intellectual reserves?
2. How much does the parent already know?
3. How much does the parent want to know?
4. How should the doctor proceed if the parent knows but will not admit?
5. What is the personal meaning of the child's health problems to the parent? (p. 14)

Pediatricians must also be able to explain health problems and treatments in ways that children will comprehend. Parents and children need understandable information from doctors and opportunities to ask

questions in order to successfully manage medical problems (Wolfson and Bass, 1979; Kupst et al., 1975). Zakus et al. (1976) identified nine specific behaviors which are related to effective parent-child-pediatrician communication:

1. Clarify purpose of the visit by mutual discussion (for example, "Why are you here today?").
2. Really listen--do not miss the point, ignore important clues, or cut off the patient.
3. Use vocabulary geared to the patient's level--do not use medical jargon or big words.
4. Ask open-ended questions when appropriate--do not use only specific questions.
5. Devise clear and simple questions--do not ask loaded, double-barreled or multiple questions.
6. Discuss one topic at a time--do not skip back and forth.
7. Try to give feedback to the parent (for example, "Is that what you mean?")--do not assume understanding of the patient's words.
8. Try to get feedback from the parent (for example, "Can you repeat what I just said about the medicine?")--do not assume that the patient understands and agrees.
9. End the session by summarizing and explaining the next steps--do not end abruptly or ramble. (p. 328)

Three Communication Training Programs for Pediatric Residents

Teaching pediatric residents how to give parents information is a relatively new idea. The majority of communication courses in pediatric residency programs focus on interviewing skills (Cross, 1982). Helfer and Black (1978) conducted one of the first projects designed to teach pediatricians information-giving skills. Specific findings of this

study revealed deficits in residents' abilities to provide clear explanations of illnesses and treatments. Participants did not provide opportunities for parents to ask questions. The researchers recommended that program directors provide opportunities for pediatric residents to learn information-giving skills.

Wolraich and Reiter (1979) studied information-giving skills of twenty-four pediatric residents at the University of Iowa. Social workers and psychologists role-played mothers of children with serious health problems. Residents were videotaped in four simulated situations: (1) telling the mother of a newborn baby that the child has Down's syndrome; (2) talking with the mother of a multiply-handicapped toddler who has just moved into the physician's area and is seeking medical care; (3) discussing the need for psychometric testing of a developmentally delayed child with a mother who is resident to the idea; and (4) dealing with a parent who is suspected of child abuse (p. 775). Reviews of videotapes revealed several common patterns of behavior. Many residents used medical jargon and technical terms when discussing medical problems and treatments. Most residents did not encourage parents or reinforce their ability to deal with a difficult situation. Finally, many residents provided parents with medical information without first checking the extent of their previous knowledge and without checking how much the parent was able to understand (p. 776). Wolraich and Reiter concluded that further research is needed to determine effective ways to improve pediatric residents' information-giving skills. Results of the study strongly indicated that pediatricians need to be trained to provide information to parents especially in stressful

situations:

> The need for instruction in this area is important because of the psychological strain such encounters place on the physician. It is emotionally difficult to communicate distressing news to parents or patients. Physicians unconsciously develop mechanisms to cope with such situations, and some of these coping mechanisms in fact hinder the physician's ability to communicate. For example, they may cause the physician to appear cold and uncaring when, in actuality, it is deep concern which is affecting his behavior. It is therefore of the utmost importance that communication skills, as they relate to providing information under stressful situations, be systematically taught to physicians-in-training. (p. 774)

"New Directions in Care for the Handicapped Child" is an inservice program developed in 1980 by Jean Lockhart, M.D. and nearly fifty other medical educators with support from the American Academy of Pediatrics. This project, which was designed to train physicians serving handicapped children, identified the following objectives and follow-up activities for providing information to parents:

1. Short-term objectives:

    a. To inform
    b. To comfort and assist through crisis
    c. To answer immediate questions
    d. To lay foundations for supportive and trusting relationships
    e. To gather information about family's strengths and weaknesses (needed for long-term guidance)

2. Guidelines for follow-up activities:

    a. To support and counsel the family through the many crises that will arise
    b. To direct the parents to various resources, either for the handicapped child or themselves
    c. To encourage family to develop unique solutions to their difficulties (p. 2)

The training program also includes information for pediatricians about possible impacts of having a handicapped child on parents and siblings. This project is used to train pediatricians at the Rose

Kennedy Center for Research in Mental Retardation and Human Development at the Bronx Municipal Hospital Center. An evaluation of the project was not available at the time of this report.

As stated previously, the majority of research and training related to communication has involved teaching interviewing skills to medical students. Few programs for pediatric residents exist, despite recommendations made by researchers. Further training and research related to teaching specific communication skills should be conducted (Helfer and Black, 1978; Werner et al., 1979; Cross, 1982; Wolraich and Reiter, 1979). Medical educators should plan courses which include the following features:

a. The essential elements of relationships skills are isolated, defined, and systematically taught;

b. The students practice the skills in either simulated or actual interpersonal situations;

c. Immediate feedback on student performance is given;

d. Training takes place in relatively small groups in order to individualize instruction; and

e. The dynamics of group process are utilized to promote both support and simulation for learning. (Pacoe, 1976, pp. 748-749)

There is currently no available literature which specifically suggests that pediatric residents be trained to communicate with school personnel.

Self-Reports as a Research Method

Several types of research methods are used to evaluate quality and effectiveness of educational and health care programs. Frequently used

methods include objectively-scored tests, direct observations, interviews, surveys, and self-reports (Wiersma, 1969). These methods are also used to measure clients' or students' satisfaction with programs. Records and diaries are sometimes used to study behaviors and program service use (Patrick and Elinson, 1979). This section of Chapter II will focus on the adequacy of self-reports as a research method.

Self-reports are used to obtain written or oral information from subjects. When this type of research method is used, the researcher must assume that respondents "have the self-awareness to recognize their own beliefs and feelings and the ability to articulate them" (Henerson et al., 1978, p. 21). Self-reports should obviously not be used with subjects who are unwilling or unable to express their beliefs and feelings.

Self-reports are commonly used in interviews or are mailed to respondents. When self-reports are sent out, subjects are usually given adequate time to think about answers before responding or to change what they have written. Anonymity of subjects is also guaranteed.

There are several advantages to using self-reports in interview situations. Subjects cannot read ahead, change answers, or be influenced by other respondents' answers. Self-reports can be used to obtain information from individuals who have poor reading or writing skills. The interviewer can clarify wording and note when a respondent does not understand questionnaire items. In addition, researchers usually have a greater chance of obtaining information from subjects who are selected for an interview than from subjects who are asked to read, complete, and return a questionnaire (Henerson, et al., 1978).

However, interviews are often time-consuming and more expensive than mailed questionnaires. In addition, an interviewer can inhibit subjects or cause them to modify their answers:

> Questioning people orally in a formal situation can make them anxious. They become worried about why they are being questioned, what they are expected to say, and how their responses will be interpreted by the person asking the questions. Their apprehensions are not completely absent in situations where people are asked to respond to questionnaires; but at least a questionnaire does not demand sitting there, being looked at.
>
> Nor can a questionnaire smile, frown, raise an eyebrow, which an interviewer in some cases will do, in spite of honest efforts to avoid influencing the respondent. (Henerson, et al., 1978, p. 27)

Self-reports are frequently used to measure respondents' attitudes. The adequacy of these instruments depends on several factors. First, the sophistication of respondents must be considered. Some people may refuse or be unable to provide personal information associated with attitudes (Wiersma, 1969).

In addition, interviewers must possess skills which will enable them to obtain information without influencing subjects' responses (Moser and Kalton, 1972). Finally, interviewers must be able to accurately and efficiently record and code answers.

Developing an adequate self-report form requires careful construction of the instrument (Patrick and Elinson, 1979). Researchers who are evaluating effectiveness and quality of health care programs should define research problems in relation to the clients who are being served. Research objectives should be precisely stated, and populations to be studied should be identified. If these steps are followed in planning a self-report, researchers are more likely to conduct an

efficient study (Moser and Kalton, 1972).

Questions contained in self-reports must be worded and ordered so that subjects will be able to easily understand and respond to items. Questions should be constructed in a way that does not threaten or offend respondents, or strain their memory (Isaac, 1978). Wording and order of questions, layout and printing, definitions, and instructions should all be considered when evaluating the quality of a self-report instrument (Moser and Kalton, 1972).

Self-reports may be designed to require forced-choice responses or answers to open-ended questions. Forced-choice responses are frequently used in self-reports which measure attitudes. This type of response usually increases consistency of measurement and general reliability of the instrument. Data can be more easily analyzed and interpreted. However, because subjects are required to choose one response, this type of measurement may not accurately record a person's true attitudes or feelings about the topic being researched.

Answers to open-ended questions are often difficult to record, code, and interpret. Subjects may provide more information than is necessary. However, these questions, which allow interviewers to probe subjects' responses, often elicit unexpected answers which are important to the researcher (Wiersma, 1969).

An adequate self-report instrument also includes a response sheet for recording answers. Forced-choice responses may be pre-coded for computer analysis. Self-reports and response sheets should always be pre-tested with a small sample of subjects who are representative of the population to be studied (Isaac, 1978).

Although it is possible to develop and administer a valid and reliable self-report instrument, this form of survey research has several faults. Some respondents may object to being asked about attitudes and will not provide truthful responses. Memory errors may also contaminate data (Isaac, 1978). Interviewers may directly or indirectly cause subjects to modify their responses. Researcher bias may adversely affect interpretation of data, especially when open-ended questions are used. Finally, respondents may provide "socially acceptable" answers rather than report their true feelings or attitudes.

However, a self-report instrument which is valid, reliable, sufficiently pre-tested, and administered according to specified directions can serve as an adequate research tool (Isaac, 1978). Self-reports must contain items which can be easily understood by subjects. If a written questionnaire is being used, clear directions must be included at the beginning of the instrument. In addition, respondents should be told why the study is being conducted and what the researcher will do with the results.

Self-reports which are used to evaluate effectiveness and quality of service-delivery programs must be pre-tested and correctly administered. In addition, data obtained should be accurately tabulated, analyzed, and interpreted.

C H A P T E R III

METHODOLOGY

The first chapter outlined the intent and findings of a study completed in 1978 by Stein, Jessop, and Reissman at Bronx Municipal Hospital Center. This chapter will describe the methodology of this project, which was conducted in the same setting as the work by Stein et al. Chapter III will focus on the following areas:

-- Design of the Study

-- Population and Sampling Procedures

-- Setting of the Study

-- Questionnaire Development

-- Data Collection Procedures

-- Data Analysis Methods

Design of the Study

This study was a non-experimental ex-post facto research project which relied on self-reports of mothers and pediatric residents. Interviewer-administered questionnaires with forced-choice responses were used in the study. The researcher selected and interviewed samples of mothers and residents. Data collected during interviews were recorded by the researcher.

Population and Sampling Procedures

This study included samples of pediatricians and mothers of asthmatic children. Specific criteria for each sample were established by

the researcher. Pediatric resident physicians who were in their first, second, or third year of residency training at Jacobi Hospital were invited to be interviewed. Criteria for mothers of asthmatic children were more specific, and were based on factors related to their child's age and illness. Mothers who had a child between the ages of five to twelve who had been hospitalized for asthma at Jacobi Hospital at least once before November, 1981, were asked to participate in the study. More details about the selection procedures were included in a later section of this chapter.

Setting of the Study

All data was collected at Bronx Municipal Hospital Center in New York City. The Bronx Municipal Hospital Center is an 868-bed general teaching hospital built in the 1950s and administered by the Health and Hospitals Corporation of the City of New York. The Center is part of The Albert Einstein College of Medicine and Montefiore Hospital and Medical Center. This medical complex, which includes five hospitals, is the major health resource for the 1.5 million people of the Bronx. In addition, patients are referred from other health centers in New York City, New Jersey, Southern Connecticut, and southern counties of New York State.

Bronx Municipal Hospital Center contains two hospitals, Abraham Jacobi and Nathan B. Van Etten. The specific catchment area for the Bronx Municipal Hospital Center is the northeast Bronx, which has a population of approximately 500,000. Demographic trends reflect an increasingly younger population among minority groups. Children and

adolescents, ages six to twenty, comprise one-third of the entire population of the northeast Bronx. A large number of patients treated at Bronx Municipal Hospital Center are Black and Hispanic, and receive health care through the Medicaid program.

All data for this study were collected at Jacobi Hospital from November 21 to December 31, 1981. The pediatric in-patient area has 58 beds and a seven-bed intensive care unit. In addition, children may receive care in a pediatric Emergency Room, a pediatric Ambulatory Care Clinic, for continuity care, and several subspecialty clinics. A total of 118,046 children were treated at Jacobi Hospital in 1980. Table 2 provides a breakdown of numbers of children treated in each area in the Department of Pediatrics.

TABLE 3

NUMBER OF CHILDREN TREATED AT JACOBI HOSPITAL, 1980

Area	Number of Children Treated
Pediatric Emergency Room	80,831
Ambulatory Care and Subspecialty Clinics	34,366
In-Patient Area	2,849
	N = 118,046

Physician care is provided by attending physicians who are members of the faculty of The Albert Einstein College of Medicine, pediatric resident physicians, and medical students at Albert Einstein. Other staff

members in the Department of Pediatrics at Jacobi Hospital include registered nurses, pediatric nurse-practitioners, pediatric social workers, and two child life activity therapists. Data collection sites for mothers' interviews included the pediatric Emergency Room, the pediatric Ambulatory Care Clinic, and the pediatric in-patient area, which are described as follows.

Pediatric Emergency Room

Emergency care for children at Jacobi Hospital is provided in a special emergency department which is located next to the adult Emergency Room. The pediatric Emergency Room was set up in 1971 in response to the high numbers of children admitted for emergency treatment in this area of the Bronx, and is staffed by nurses and physicians with pediatric training. Two of the ten treatment rooms are used only to take care of asthmatic children. A triage system has been established in which asthmatic patients are seen immediately by a nurse, while the more severe cases are treated by a physician. Approximately 5,000 children per year are treated for asthma in the Emergency Room at Jacobi Hospital. Ten percent, or 500, of these children are admitted for in-patient care. Follow-up appointments in the Ambulatory Care Clinic are scheduled for each child who is treated for asthma in the Emergency Room. Asthmatic patients who return to the Emergency Room within 24 hours of their first visit are usually admitted to the hospital. In severe cases, a hospital social worker can be paged Monday through Friday, 9:00 A.M. to 5:00 P.M.

Pediatric In-Patient Area

The pediatric in-patient area is on the eighth floor of Jacobi Hospital. Most rooms contain four beds, with the exception of four single and four double rooms. Visiting hours for parents are unlimited in this department, although there are no sleeping facilities for parents who remain overnight. Not all rooms have chairs for visitors, and parents frequently have to sit on their child's bed. Children are permitted, when medically possible, to walk around the in-patient floor, although most children seemed to remain in their rooms watching television. There is a pediatric play room on the eighth floor, but program activities are typically designed for infants and toddlers. As a result, many of the school-aged patients remain isolated in their rooms.

The entire in-patient area has a dreary appearance, and walls in most rooms have cracked and peeling paint. There is a noticeable amount of dirt on the floors, and cockroaches can frequently be seen crawling across walls, and sometimes over children's bedside tables. Several rooms had broken windows which took many weeks to be repaired. During one interview, the child sat in bed with his coat on. The mother had used her son's pillow to block the cold air which was blowing through the broken window. The outside temperature was 25°F at the time of the interview. Many children had only one blanket on their beds, and no extra bedding was available. During another evening interview, the researcher noticed several large pieces of broken glass on the floor next to a child's bed. The ten-year-old girl needed to go to the bathroom at the end of the hall. The interviewer spent one-half hour trying

to locate someone to remove the glass, and was told by the head nurse and the chief resident, in separate conversations, that there was no one who was responsible for removing broken glass. Furthermore, a written request would have to be submitted, processed, and approved by the hospital's general housekeeping department which would be open at 9:00 A.M. the next day. The chief resident finally agreed to unlock a closet and give the researcher a broom to remove the glass herself.

Patients and parents were able to ring for a nurse from their bedsides, although most parents seemed to go directly to the nurses' station to make a request. This researcher observed that nurses and parents had few interactions which were not medically related. Nurses appeared to spend little time in patients' rooms and often left as soon as medications had been given or a medical chart was filled in. Consequently, when children did not have visitors, they were usually alone in their rooms. It seemed that physicians also had little contact with children except during medical rounds.

Because of the shortage of space on this floor, there is no room or lounge provided specifically for parents. Adults, when they wish to smoke or simply have a break, often go to a small area directly in front of the elevators. There are no chairs in this area, but many parents nevertheless seem to take advantage of the only place on the floor where they can have some privacy. Additionally, there is no room on the floor where physicians and nurses can talk with parents. The shortage of space is one of the many problems that seem to exist in the in-patient department. On most days, 100% of the 58 available beds are filled. As stated previously, not all beds have adequate blankets or pillows. The

researcher observed that three mothers who participated in the study brought extra blankets and pillows from home for their children.

Pediatric Ambulatory Care Clinic

Continuity care is provided in the Pediatric Ambulatory Care Clinic which is located in the basement of Jacobi Hospital. The clinic is staffed by attending physicians, nurses, pediatric nurse-practitioners, social workers, and pediatric resident physicians. The clinic is open Monday through Friday, with appointments scheduled from 9:00 A.M. to 12:00 Noon and 1:00 P.M. to 4:00 P.M. Chairs for children and adults are provided in the clinic hallway. At the time of this study, however, several chairs were broken, and some parents and children had no place to sit while they waited for their appointments.

In most cases, children are seen by the same practitioner for every visit. Babies, young children, and adolescents come to this clinic for well-child care, intermittent health problems such as earaches or colds, and for follow-up visits after being discharged from the Emergency Room or in-patient floor. All asthmatic patients who are treated in the Emergency Room are seen no more than one week later in the Ambulatory Care Clinic. The Department of Pediatrics also has several sub-specialty clinics, including a Pulmonary Clinic where severe cases of asthma are treated on an out-patient basis.

Interviews with pediatric resident physicians were conducted in the Triage Room in the Ambulatory Care Clinic and in the chief resident's office on the in-patient floor. Both rooms were ideal for interviews because privacy was guaranteed and no interruptions occurred.

Most residents' interviews were conducted in the evenings in the chief resident's office.

Questionnaire Development

Separate questionnaires were developed for interviews with mothers and residents. Several steps, which are described in this section, were followed in the process of designing questionnaires.

The researcher had identified "support" and "information" as the two major areas of pediatrician-mother communication to be studied. The first step involved identifying the following four main areas related to giving and receiving information and support:

(1) Emotional support provided to mothers of asthmatic children.

(2) General information about asthma.

(3) Information about home care of asthmatic children.

(4) Information about school care of asthmatic children.

The researcher developed a list of twenty-eight behaviors related to the four areas of support and information. Six attending physicians agreed to participate in a pilot study of the first questionnaire to help determine content validity. Respondents were asked to indicate how important it is for pediatricians to provide each of the twenty-eight behaviors listed, and to self-rate their present ability to provide these services to parents. This first test of the instrument, which is included in this report as Appendix A, was completed in June, 1981.

Participants in this review of the questionnaire indicated that the wording of several items needed to be changed and that the instrument contained too many items. The researcher then developed five questions for each of the four broad categories of support and information, resulting in a list of twenty behaviors. Several items had been re-written and questions were again randomly listed by categories. At this point, the researcher developed a similar list of items for mothers' interviews. This revised list with twenty items, which is included in this report as Appendix B, was then reviewed by nurse-practitioners in the Department of Pediatrics. The purpose of their review of items was to determine content validity of mothers' questionnaires. Nurse-practitioners were asked to evaluate the list using the following set of questions as a guide:

(1) Will mothers be able to understand each question?

(2) Which items on the list are irrelevant or repetitive?

(3) Are there any items related to giving information or support to asthmatic children's parents which should be added to the list?

(4) How could the sequence of questions be improved?

(5) In what other ways could the questionnaire be improved?

Questionnaires were distributed to nurse-practitioners on October 22, 1981, with a letter from the researcher explaining the purpose of the study (see Appendix C). Responses from nurse-practitioners' reviews consistently suggested that questions be organized according to the category "to help mothers maintain the same line of thinking." After suggested changes had been completed, the researcher then asked six attending physicians to review the residents' and mothers'

questionnaires for wording, sequence, and general format. Responses from this third review of questionnaires indicated that the instruments were adequate and needed only a few technical changes.

Based on recommendations from sixteen reviewers in three pilot tests, the researcher revised the original wording of certain questions and had also revised the order of items so that respondents would be asked sets of questions about support and information. Fourth and final drafts of mothers' and residents' questionnaires were reviewed by six attending physicians and the chairperson of this dissertation committee. At no time did pediatric residents have opportunities to see the questionnaires prior to participating in interviews.

List of Twenty Behaviors Studied:
Final Version

The revised and final version of each of the twenty behaviors is listed below, with items grouped by category. In the second part of mothers' questionnaires, respondents were asked:

> Think back for a moment about times when you have talked with your child's doctor. If he or she has done this with you, how satisfied were you when the doctor . . .

1. SUPPORT

   a. Talked with you about things that worry you about _____'s asthma?
   b. Encouraged you to call him/her if you have a problem or concern about _____'s asthma?
   c. Reassured you when you become upset when talking about _____'s asthma?
   d. Discussed specific problems or concerns you have about _____'s asthma?
   e. Helped you identify other people, like friends, relatives, or neighbors, who might help you cope with problems caused by _____'s asthma?

2. GENERAL INFORMATION ABOUT ASTHMA

a. Answered your questions about _____'s asthma?
b. Explained how asthma will affect _____ in the next few years?
c. Discussed how many months or years _____'s asthma is expected to last?
d. Suggested other people who might need to know about _____'s asthma, like friends or relatives who live with you or spend a lot of time with _____?
e. Gave you materials, like books or pamphlets, which explain how to take care of a child with asthma?

3. INFORMATION FOR CARE OF CHILD AT HOME

a. Explained what to do if _____ has an asthmatic attack at home?
b. Explained how _____'s asthma medicines help him/her?
c. Explained how to give _____ asthma medicine?
d. Talked with you about how well other people in your household would be able to take care of _____ during an asthmatic attack?
e. Explained how to control some things which might cause _____'s asthma attacks, like dust or certain foods?

4. SCHOOL-RELATED QUESTIONS

a. Talked with you about how often _____ has asthmatic attacks during the school day?
b. Talked with you about keeping _____'s asthma medicine in school in case of an attack?
c. Talked with you about how well _____'s teachers would be able to take care of _____ during an asthmatic attack?
d. Discussed how asthma affects _____'s ability to learn and do school work?
e. Talked with you about how asthma restricts _____'s physical activities at home, or in school gym classes and recess periods?

Each mother was given a card with the following list of possible responses:

(1) My child's doctor has done this and I was very satisfied.

(2) My child's doctor has done this and I was satisfied.

(3) My child's doctor has done this and I was not satisfied.

(4) My child's doctor has never done this, but I would like him or her to.

(5) I don't need to expect the doctor to do this.

The researcher read this list of choices to each mother at the beginning of this part of the interview, and explained that the mother would have to choose one answer.

In the next part of the interview, mothers were asked to identify the person whom they most wanted to provide each of the twenty services. Again, mothers were handed a card with choices listed and asked to give only one answer.

Residents' questionnaires contained an identical list of behaviors. Grammatical changes were made so that questions made sense to residents. For example, "Talked with you about things that worry you about _____'s asthma" was changed to "Talking with mothers about things that worry them about their child's illness." Respondents were given a set of cards with the following choices:

(1) I have been very effective.

(2) I have been effective.

(3) I have been somewhat effective.

(4) I have not been effective.

(5) I have never done this before.

Each resident was asked, "In general, how effective do you think you've been when you've spent time . . .", and was asked to give one response only to each question. In the next section of the questionnaire, residents were asked to identify the "Ideal Provider" for each service, and were given a card with the same choices listed on mother's cards. Questionnaires were intentionally designed in this way to enable the researcher to compare mothers' and residents' responses. Final versions of both instruments and cards listing response choices are provided in this report in Appendix F (Mothers') and Appendix G (Residents').

Answer sheets for mothers' and residents' responses were developed and coded, along with questionnaire items, for computer analysis. The researcher was then required to submit a description of the study, along with both sets of instruments and answer sheets, to the Committee on Clinical Investigations at The Albert Einstein College of Medicine. Materials sent to this Committee are included in this report in Appendix C. Ruth Stein, M.D., agreed to serve as faculty sponsor of the project, which was submitted for Committee approval on November 16, 1981, to I. Herbert Scheinberg, M.D., Chairperson of the Committee. On November 19, 1981, the researcher received approval to begin the study. Regulations established by the Committee on Clinical Investigations required the researcher to obtain written informed consent from each participant in the study (see Appendix E).

Summaries of Mothers' and Residents' Questionnaires

Mothers' revised and approved questionnaires (see Appendix F) included the following sections:

Part I: Information about child (sex, age, number of previous hospitalizations for asthma, grade level in school, medications currently taken by child to control asthma).

Part II: Rating of pediatrician's skills in providing each of the twenty behaviors listed.

Part III: Identification of "Ideal Provider" for each of the twenty behaviors listed.

Part IV: Mother's perceptions of teacher's knowledge of child's asthmatic condition.

Part V: Demographic information about mother.

Part VI: Interviewer's observations of mother's apparent verbal fluency, ease, and overall attitude during interview.

Pediatric residents' revised and approved questionnaires (see Appendix F) included the following sections:

Part I: Self-rating of ability to provide each of the twenty behaviors listed.

Part II: Identification of "Ideal Provider" for each of the twenty behaviors listed.

Part III: Resident's attitudes toward working with asthmatic patients and their families, and attitudes about the value of providing communication-training opportunities to pediatricians.

Part IV: Demographic information about resident.

The researcher interviewed five mothers of school-aged asthmatic children to determine possible problem areas of respondents' comprehension. All interviews proceeded without complications, and responses from these initial interviews were included in the final data base.

Twelve second-year pediatric residents were also interviewed to determine possible problem areas of respondents' comprehension.

Similarly, all residents' interviews proceeded smoothly and responses were included in final data sets.

Data Collection Procedures

Residents' Interviews

Once questionnaires had been approved by the Committee on Clinical Investigations, the researcher sent letters to each of the fifty-seven pediatric residents (see Appendix H). The letter introduced the researcher as a doctoral candidate at the University of Massachusetts and provided a brief description of the study. Subjects were assured that responses would be treated confidentially and would not be used for any form of evaluation. Residents were invited to call the researcher in her office at Jacobi Hospital or at home if they had any questions about the intent of the project. Subjects were asked to return a form indicating times and places they would be available for interviews. An envelope with the researcher's name was taped to the wall of the Triage Room in the Pediatric Ambulatory Care Clinic, and residents were instructed to place completed forms in that envelope. This room was selected because each resident spent two half-days per week working in the Ambulatory Care Clinic.

The researcher kept records of the first-, second-, and third-year residents who returned forms. Selection of residents who were interviewed was determined by identifying the first twelve individuals in each year of training who returned forms. Although the researcher had requested that forms be returned to the Triage Room by November 24, 1981, thirty-six residents (twelve in each year of

training) returned forms by November 21, 1981. The first interview occurred on November 22, 1981. Interviews with all thirty-six respondents were completed by December 31, 1981.

The same process was followed in each interview. The researcher first gave the resident a copy of the informed consent form to read and sign. The interview was then begun. Each interview lasted approximately twenty minutes. Residents were given cards with response choices listed (see Appendix G). These cards were used for answering self-rating questions since a specific response was required. Cards were also used for questions about "Ideal Provider."

In summary, selection of participants was determined by identifying the first thirty-six residents who agreed to participate in the study. Residents at Jacobi Hospital were overwhelmingly cooperative, as evidenced by the rapid return of consent forms.

Although each resident had identified a specific time and location for an interview, this sytem was actually inefficient because of physicians' hectic schedules. In response to this, the researcher began to wait in the Ambulatory Care Clinic, the Emergency Room, and the staff lounge on the in-patient floor for residents who had some free time for an interview. This informal procedure was extremely time consuming, but was an effective way for the researcher to complete all interviews by the December 31, 1981, deadline.

The two chief residents and several attending physicians in the Department of Pediatrics provided great assistance by sending residents who had free time to the area where the researcher was waiting. Many of these attending physicians had been assisting the researcher since

June as reviewers of the first drafts of the questionnaires. They continued to express interest in and support for the study by encouraging the residents to participate in the project. Many of the respondents requested a summary of the findings and encouraged their peers to complete interviews. This support certainly helped the researcher complete interviews by the December 31, 1981, deadline.

Mothers' Interviews

The researcher conducted interviews with mothers from November 21, 1981 through December 31, 1981. Mothers who participated in the study each had a child between the ages of five to twelve years who had been hospitalized at least once before November for asthma.

All interviews with mothers took place in Jacobi Hospital in the pediatric Ambulatory Care Clinic, the pediatric in-patient area, or in the pediatric Emergency Room. The researcher reviewed patients' charts in each area to identify mothers who were eligible for participation in the study. One-hundred percent of mothers approached by the researcher agreed to participate in the study. This perfect response rate may be explained in several ways. First, the researcher observed that many mothers seemed anxious to have something to do while waiting at the hospital. In addition, mothers seemed to enjoy talking to someone about their child's illness.

As soon as a mother agreed to be interviewed, the researcher read the informed consent form to the mother. This was done because although all respondents spoke English, the researcher could not assume that mothers' comprehension of written English was adequate. This procedure

took no more than five minutes, and all mothers signed consent forms. It is important to mention at this point that because Jacobi is a teaching hospital, many research projects are completed in this setting. Several mothers indicated that they had participated in previous studies, although not all recalled having had an opportunity to refuse to participate. Three mothers reported that this was the first time they had seen an informed consent form, although they recalled having been interviewed for other studies.

Each interview lasted approximately twenty minutes. In several interviews, interruptions occurred for interesting reasons. In an interview on the in-patient floor, the researcher had to stop the session to kill a cockroach that had crawled across the bedside table on which the researcher was writing. Several interviews were interrupted when nurses or doctors came to see the child and the mother was understandably distracted for a few minutes.

The researcher selected mothers herself rather than rely on health care providers to identify respondents. This was done to prevent possible contamination of mothers' responses. In other words, if a mother were told by her pediatrician that a researcher wanted to ask her how satisfied the mother was with the quality of care her child was receiving, it is possible that some mothers would be afraid that the pediatrician would have access to her answers. Each mother was assured that all responses would be kept confidential and was specifically requested not to mention her pediatrician's name during the interview. At no point during the study did the researcher attempt to identify names of residents' asthmatic patients.

Validity

Content validity must be demonstrated when working with instruments which measure attitudes or self-ratings (Henderson, 1978). Content of the twenty behaviors studied was evaluated by a group of sixteen health care professionals. Each of these professionals has clinical experience working with mothers of asthmatic children and pediatric resident physicians. Judges completed three separate reviews of mothers' and residents' questionnaires. Content validity was determined by judges' approval of final versions of both instruments.

Reliability

Reliability coefficients (Cronbach's α) were developed for the list of twenty behaviors studied in mothers' and residents' questionnaires. Scores were calculated for mothers' instruments (.91) and for residents' instruments (.88). On the basis of these reliability scores, none of the twenty items was eliminated from the study before the data were analyzed.

Data Analysis Methods

Questionnaires and answer sheets were coded for computer analysis of data. The Statistical Package for the Social Sciences (Nie et al., 1975) was used to perform data analysis. Frequencies of all responses were calculated for descriptive analysis of data. Frequencies of demographic data were used to describe sample populations. For purposes of accurate statistical analysis of differences between mothers' and residents' ratings and self-ratings of the twenty behaviors studied,

revision of rating choices for both groups was necessary. Revised rating systems are as follows:

Mothers' Choices	Residents' Choices
1. Very Satisfied	1. Very Effective
2. Satisfied	2. Effective
3. Not Satisfied	3. Not Effective
4. Not Needed	4. Never Done Before

This change in ratings was made so that analysis of differences could be computed more effectively. Chi-square scores were calculated for each item, as well as p-values. Statistical significance of differences between mothers' and residents' responses to each item was determined by studying p-values. This process was also followed for analysis of data from sections of questionnaires in which mothers and residents were asked to identify "Ideal Providers" for each of the twenty behaviors listed.

CHAPTER IV

RESULTS OF THE STUDY

Statistical and descriptive analyses of data are presented and discussed in this chapter in the following order:

-- Description of participants

   (a) Profile of mothers

   (b) Profile of pediatric residents

-- Presentation of participants' ratings and self-ratings of twenty behaviors studied: Data are presented in tables listing percentages, Chi-square figures, and p-values. Results of participants' choices of "Ideal Providers" are also presented in this section.

-- Presentation of mothers' responses to questions regarding ability of school personnel to provide adequate care to asthmatic children.

-- Presentation of residents' responses to questions regarding communication training and working with asthmatic patients.

Description of Participants

Profile of Mothers

Thirty mothers of asthmatic children, ages five to twelve years, participated in this study. The final section of mothers' interviews included nine demographic questions which are summarized as follows.

The mean age of mothers was 33.0 years, with an age range of 20.0 to 40.0 years. Twenty-one mothers were married; 5 were single and had never married. One mother was divorced, one was widowed, and two mothers were separated at the time of their interviews.

Seventeen respondents were Hispanic, while 5 were Caucasian and 8 were Black. Nineteen mothers were born in the United States, while 11 were born outside the United States. Twenty-five respondents reported that English was the primary language spoken in their home, while 5 stated that Spanish was spoken most often in their household. The mean number of individuals living in respondents' homes was 4.1 persons.

Twelve mothers interviewed had completed some high school, 4 had completed eighth grade or less, 6 had graduated from high school, and one mother had finished college. Six mothers had attended college for one to three years. In addition, one mother had attended business school after high school.

Financial status of mothers varied. Fourteen worked part-time, 2 mothers worked full-time, and 5 received unemployment benefits. Two mothers reported that they receive Aid to Dependent Children (Welfare), one mother received Social Security payments, and another received Supplementary Security Income. Three mothers received interest from savings, while two mothers received pension payments. Almost one-half of the mothers depended on wages from part-time employment to support their families.

The financial part of mothers' interviews included questions about the child who was receiving health care at Jacobi Hospital for asthma. For purposes of the study, interviews were conducted only with mothers whose elementary school-aged children had had at least one previous hospital admission for asthma. Eighteen children were males; 12 were females. Children's ages ranged from 5.0 to 12.0 years, with 8.5

being the mean age. Grade span was from kindergarten through Grade 6. Nineteen children attended public schools, 7 attended parochial schools, and 4 attended private schools. Twenty-three mothers reported that Jacobi Hospital was the only medical facility to which they bring their child for treatment of asthma, while 7 went to other health centers to receive care for their child's asthma.

The mean number of hospitalizations for asthma prior to participating in this study was 7.4 per child. Minimum number of hospitalizations was 2, while one child had been hospitalized for asthma more than 50 times. Seven mothers reported that asthma medicines were presently kept at their child's school. Twenty-three reported that their child did not need to take medications while at school.

At the end of an interview, the researcher completed "Interviewer's Observations" of each mother. The researcher informally evaluated respondents' verbal proficiency, ability to understand questions, apparent ease during the interview, and overall attitude during the interview. Summaries of these ratings, which were entirely subjective and based only on the researcher's perceptions, are presented in Tables 4 and 5.

The researcher limited the sample of mothers to include only English-speaking respondents. Twenty-eight of the 30 mothers appeared to understand and speak English well enough to complete the interview. All mothers seemed able to understand questions asked during interviews.

TABLE 4

RESPONDENTS' VERBAL PROFICIENCY

Ratings	Mothers (N=30)
High	15
Medium	13
Low	2

TABLE 5

ABILITY OF RESPONDENTS TO UNDERSTAND SENSE OF THE QUESTIONS

Ratings	Mothers (N=30)
Little Understanding	0
Moderate Understanding	15
Good Understanding	15

The majority of respondents (26) appeared relaxed throughout the interview, while 4 remained or became uneasy. The researcher noted that one mother who "became less at ease" seemed to become tense when asked about source of income. Two mothers, at this point in the interview, asked for confirmation that responses would be kept confidential. The

majority of mothers (26) appeared to have friendly and cooperative attitudes toward the interview, while 4 seemed indifferent or hostile.

Profile of Pediatric Residents

The final section of residents' interviews included nine demographic questions which are summarized as follows.

Twenty-one resident interviewed were male; 15 were female. The mean age of respondents was 27.5 years, with a range of 23.0 to 33.0 years. Seventeen were married; 19 were single. Thirty-two residents did not have children, while 4 had at least one child.

The majority of residents (30) had completed their pre-college education in the northeast, 2 in the mid-west, 2 in the far west, and 2 outside the United States. The majority of respondents (34) were Caucasian and 2 were Black. Twenty-eight planned to work in a large city after completing residencies, two would like to work in a suburb, and the remainder (6) planned to work in a small or medium-size city. None is planning to practice medicine in a rural or farm community.

Presentation of Mothers' and Residents' Ratings of Twenty Behaviors Studied

Mothers' and residents' responses to each of the twenty behaviors studied are presented in this section. Behaviors have been divided into four broad categories, with five items assigned to each category (see Page , Chapter III). Mothers' ratings of satisfaction and residents' self-ratings of effectiveness, as well as identification of "Ideal Provider" are presented for each item. Number of participants' responses are included. Chi-square figures and p-values have been

calculated to establish statistical significance of differences between mothers' and residents' ratings of each item. Tables 6 and 7 contain data for Items 1-5, Tables 8 and 9 contain data for Items 6-10, Tables 10 and 11 contain data for Items 11-15, and Tables 12 and 13 contain data for Items 16-20. Specific behaviors described by data are listed before each set of tables.

Category 1: Emotional Support for Mothers of Asthmatic Children

Item

1. Talked with you about things that worry you about _____'s asthma.
2. Encouraged you to call him/her if you have a problem or concern about _____'s asthma.
3. Reassured you when you became upset when talking about _____'s asthma.
4. Discussed specific problems or concerns you have about _____'s asthma.
5. Helped you identify other people, like friends, relatives, or neighbors, who might help you cope with problems caused by _____'s asthma.

Statistics for Items 1-5 are included in Tables 6 and 7.

TABLE 6

MOTHERS' AND RESIDENTS' RATINGS OF ITEMS 1-5

	Item 1	Item 2	Item 3	Item 4	Item 5
Residents (N=36)					
Very Effective	1	5	5	4	1
Effective	32	12	30	32	13
Not Effective	2	12	--	--	8
Never Done	1	7	1	--	14
Mothers (N=30)					
Very Satisfied	9	9	7	7	4
Satisfied	14	18	18	18	7
Not Satisfied	7	3	3	4	12
Not Needed	--	--	2	1	7
Chi Square	16.81	14.32	6.17	9.27	6.24
p-value	<.001	<.01	>.1	<.05	>.1

TABLE 7

MOTHERS' AND RESIDENTS' SELECTIONS OF
IDEAL PROVIDER FOR ITEMS 1-5

	Item 1	Item 2	Item 3	Item 4	Item 5
General Pediatrician					
Mothers	5	12	10	9	9
Residents	27	27	29	34	13
Asthma Specialist					
Mothers	23	14	12	19	7
Residents	1	1	1	2	--
Other					
Mothers	2	4	8	2	14
Residents	8	8	6	--	23
Chi Square	38.67	17.97	18.46	30.00	9.45
p-value	<.001	<.001	<.001	<.001	<.01

Discussion

Category 1: Emotional Support for Mothers of Asthmatic Children

This area of study included five items related to emotional support provided to mothers of school-aged asthmatic children. Specific behaviors studied in this section included residents' skills in talking with mothers about worries or concerns they have regarding their child's illness, and in helping mothers identify sources for emotional support.

The majority of residents (33) reported that they were effective or very effective in talking with mothers about things that worry them (Item 1), and the majority of mothers (23) were satisfied or very satisfied with this service. However, almost one-quarter of the mothers were not satisfied, while only 2 residents stated that they were not effective in this area. The p-value for the chi-square was $<.001$, indicating a highly significant difference between mothers' and residents' responses to this item.

Differences between mothers' and residents' responses appeared to go in the opposite direction for Item 2, with the majority of mothers (27) indicating satisfaction with their pediatrician's skills in encouraging mothers to call with worries or concerns. More than one-half of the residents reported that they were not effective in this area or that they had never encouraged mothers to call. The p-value for the chi-square was $<.01$, again indicating statistical significance for this difference.

All 36 residents reported that they were effective or very effective when discussing specific problems or concerns about a child's condition with mothers (Item 4). The majority of mothers (25) were

satisfied or very satisfied, while only 4 were not satisfied. A p-value of <.05 indicated moderate statistical significance of differences between mothers' and residents' responses.

P-values for Items 3 and 5 were >.1. No significance existed between mothers' and residents' ratings for these items. The majority of residents (35) reported that they were effective when reassuring mothers who became upset about their child's illness; 25 mothers were satisfied. Although no residents felt that they were not effective in this area, 3 mothers stated that they were not satisfied with their pediatrician's skills in reassuring them when they became upset.

Although 11 mothers reported satisfaction with their pediatrician's skills in helping them identify other sources of emotional support (Item 5), 12 were not satisfied with this service. The majority of residents (22) stated that they were not effective or had not done this before. Almost one-quarter of the mothers felt that they did not need this service from a pediatrician.

Data describing mothers' and residents' perceptions of "Ideal Providers" for Items 1-5 are presented in Table 7. P-values for each item indicated high statistical significance between the two groups of respondents. The majority of residents agreed that general pediatricians should provide each of these services to mothers. On Item 5, however, 23 residents indicated that a social worker should help mothers develop support systems. Fifteen mothers also stated that a social worker or psychologist could help them with this service.

P-values for "Ideal Provider" ratings indicated highly significant differences between mothers' and residents' perceptions. Mothers seemed

to want asthma specialists to provide support-related behaviors, while residents generally agreed that a general pediatrician should be helping mothers with services described in Items 1-5.

Category 2: General Information About Asthma

Item

6. Answered your question about _____'s asthma.

7. Explained how asthma will affect _____ in the next few years.

8. Discussed how many months or years _____'s asthma is expected to last.

9. Suggested other people who might need to know about _____'s asthma, like friends or relatives who live with you or spend a lot of time with _____.

10. Given you materials, like books or pamphlets, which explain how to take care of a child with asthma.

Statistics for Items 6-10 are included in Tables 8 and 9.

TABLE 8

MOTHERS' AND RESIDENTS' RATINGS OF ITEMS 6-10

	Item 6	Item 7	Item 8	Item 9	Item 10
Residents (N=36)					
Very Effective	12	3	4	2	--
Effective	24	29	29	10	2
Not Effective	--	2	2	4	4
Never Done	--	2	1	20	30
Mothers (N=30)					
Very Satisfied	8	5	4	3	1
Satisfied	17	7	8	4	2
Not Satisfied	5	18	17	13	25
Not Needed	--	--	1	10	2
Chi Square	6.5	28.43	23.41	10.41	40.50
p-value	<.05	<.001	<.001	<.05	<.001

TABLE 9

MOTHERS' AND RESIDENTS' SELECTIONS OF
IDEAL PROVIDER FOR ITEMS 6-10

	Item 6	Item 7	Item 8	Item 9	Item 10
General Pediatrician					
Mothers	7	9	7	9	9
Residents	33	30	28	14	15
Asthma Specialist					
Mothers	20	20	21	9	14
Residents	3	3	3	1	3
Other					
Mothers	3	1	2	12	7
Residents	--	3	5	21	18
Chi Square	32.19	24.53	27.06	9.47	13.02
p-value	<.001	<.001	<.001	<.01	<.001

Discussion

Category 2: General Information About Asthma

This area of study included five items related to general information provided to mothers of school-aged asthmatic children. Specific behaviors studied in the section included residents' skills in explaining how long a child's illness might last, providing mothers with written materials about asthma in English or Spanish, and answering mothers' questions about their child's chronic condition.

All residents reported that they were effective or very effective when answering mothers' questions about asthma (Item 6). Although the majority of mothers (25) indicated satisfaction in this area, 5 were not satisfied. The p-value for this item was <.05, suggesting moderate statistical significance for the difference in responses. Although most residents (32) reported being effective or very effective when explaining how asthma will affect a child in the next few years (Item 7), more than one-half of the mothers were not satisfied with their pediatrician's ability to do this. A similar pattern of response was observed for Item 8. Thirty-three residents stated that they were effective in discussing how long a child's asthma might last, while 17 mothers were not satisfied with this service. P-values for Items 7 and 8 were <.001, suggesting high statistical significance between mothers' and residents' responses to these questions.

More than one-half of the residents (20) reported that they had never talked with mothers about other persons who might need to know about a child's asthmatic condition (Item 9). Although one-third of the mothers indicated that they did not need their pediatrician to do

this, almost one-half of the mothers were not satisfied with this service.

A significant response pattern was observed in Item 10. The majority of residents (30) stated that they had never given mothers written materials about asthma, while the same percentage of mothers indicated that they were not satisfied with this service. The p-value of <.001 suggested high significance of responses to this item.

Responses to Table 9, listing mothers' and residents' choices for "Ideal Providers," suggested that the majority of mothers would like asthma specialists to answer questions about their child's illness, explain how asthma will affect their child in the future, and discuss how long the illness might last (Items 6, 7, and 8). The majority of residents stated that general pediatricians should provide these services to parents. P-values for mothers' and residents' perceptions of "Ideal Providers" for Items 6-8 were all <.001, indicating high statistical significance.

An equal number of mothers (9) reported that general pediatricians or asthma specialists should talk with mothers about others who need information about their child's illness (Item 9). The remaining 12 mothers agreed that social workers should do this with parents. Twenty-one residents also identified social workers as the "Ideal Provider" for this service. The p-value for this item was <.01.

The last item in this category again suggested high significance of the difference between mothers' and residents' perceptions of who should provide written materials to mothers (Item 10). Eighteen residents indicated that a social worker could provide this service to

mothers, while 15 felt that a general pediatrician should do this. Fourteen mothers, however, stated a preference for an asthma specialist to provide written materials. Nine would like a general pediatrician to do this, while only 7 assigned this responsibility to the social worker. The p-value of this item was <.001, indicating a highly significant statistical difference between mothers' and residents' perceptions of an "Ideal Provider" for this service.

Category 3: Information Related to Home Care of Asthmatic Children

Item

11. Explained what to do if _____ has an asthmatic attack at home.

12. Explained how _____'s asthma medicines help him/her.

13. Explained how to give _____ asthma medicine.

14. Talked with you about how well other people in your household would be able to take care of _____ during an asthmatic attack.

15. Explained how to control some things which might cause _____'s asthmatic attacks, like dust or certain foods.

Statistics for Items 11-15 are included in Tables 10 and 11.

TABLE 10

MOTHERS' AND RESIDENTS' RATINGS OF ITEMS 11-15

	Item 11	Item 12	Item 13	Item 14	Item 15
Residents (N=36)					
Very Effective	14	7	10	0	6
Effective	21	27	26	10	26
Not Effective	1	0	--	6	2
Never Done	--	2	--	20	2
Mothers (N=30)					
Very Satisfied	6	6	10	3	5
Satisfied	12	16	17	6	13
Not Satisfied	12	8	3	14	10
Not Needed	--	--	--	7	2
Chi Square	14.54	12.45	4.37	13.02	9.29
p-value	<.001	<.01	>.1	<.01	<.05

TABLE 11

MOTHERS' AND RESIDENTS' SELECTIONS OF
IDEAL PROVIDER FOR ITEMS 11-15

	Item 11	Item 12	Item 13	Item 14	Item 15
General Pediatrician					
Mothers	13	11	13	10	6
Residents	28	31	29	20	23
Asthma Specialist					
Mothers	14	17	15	13	21
Residents	1	--	--	1	10
Other					
Mothers	3	2	2	7	3
Residents	7	5	7	15	3
Chi Square	17.96	27.49	23.52	16.12	13.43
p-value	<.001	<.001	<.001	<.001	<.001

Discussion

Category 3: Information Related to Home Care of Asthmatic Children

This area of study included five items related to specific information about home health care provided to mothers of school-aged asthmatic children. Behaviors studied in this section included residents' skills in providing information about asthma medications, how to respond when a child suffers an asthma attack at home, and how to control environmental factors which might increase a child's chances of suffering an attack.

Almost the entire sample of residents (35) reported that they have been effective or very effective when explaining to mothers how to respond when a child has an asthma attack at home (Item 11). Although only one resident stated that he/she was not effective, 12 mothers indicated that they were not satisfied with this service. However, 12 mothers stated that they were satisfied or very satisfied with their pediatrician's skills in this area. A highly significant difference, as indicated by a p-value of <.001, was measured between mothers' and residents' responses to this item.

A similar type of difference between mothers and residents was observed for Item 12. The majority of residents (34) reported that they are effective when explaining how medications work; the majority of mothers (22) were also satisfied with this service. However, 8 mothers were not satisfied with their pediatrician's skills in this area, while none of the residents reported himself or herself as "Not Effective." The p-value for this item was <.01 and indicated significance between mothers' and residents' different perceptions in this area.

Participants' responses to Item 13 indicated that the majority of mothers were satisfied with their pediatrician's instructions for asthma medications; all 36 residents felt that they were effective or very effective in this area. Only 3 mothers were not satisfied with this service. A p-value of >.1 indicated low significance between mothers' and residents' responses to this item.

Almost one-half of the mothers indicated dissatisfaction with their pediatrician's skills in talking about how other household members can take care of a child during an asthma attack (Item 14). More than one-half of the residents stated that they had never done this before with mothers. However, one-quarter of the mothers stated that they did not need their pediatrician to do this. A p-value of <.01 suggested statistical significance for differences observed in participants' responses to this item.

The majority of mothers (18) were satisfied with their pediatrician's explanations regarding environmental factors which might trigger asthma attacks (Item 15). Thirty-two residents reported that they were effective or very effective when providing this service to mothers. Only 2 stated that they were not effective, although 10 mothers were not satisfied. Moderate statistical significance was measured by a p-value of <.05.

All p-values for participants' ratings of "Ideal Providers" for Items 11-15 were <.001. The majority of residents indicated that general pediatricians should provide mothers with information related to home care of asthmatic children. One-half of the mothers wanted an asthma specialist to provide this service, although 13 stated that a

general pediatrician should discuss home care information. Mothers also expressed equal preference for general pediatricians and asthma specialists to explain how to give asthma medications.

Almost one-quarter of the mothers reported that a social worker should talk with them about how well members of their household can take care of an asthmatic child during an attack (Item 14). Fifteen residents stated that a social worker should do this. However, the majority of mothers (20) indicated that this service should be the general pediatrician's responsibility.

The majority of mothers (21) stated that an asthma specialist should discuss environmental factors which might precipitate asthma attacks (Item 15), while only 6 expected general pediatricians to do this. Residents' perceptions of the "Ideal Provider" for this service appeared to go in an opposite direction. Twenty-three reported that a general pediatrician should discuss environmental factors with mothers, and only 10 indicated that this service should be provided by a specialist.

Category 4: Information Related to School Care of Asthmatic Children

Item

16. Talked with you about how often _____ has asthmatic attacks during the school day.

17. Talked with you about keeping _____'s asthma medicine in school in case of an attack.

18. Talked with you about how well _____'s teachers would be able to take care of _____ during an asthmatic attack.

19. Discussed how asthma affects _____'s ability to learn and do school work.

20. Talked with you about how asthma restricts _____'s physical activities at home, or in school gym classes and recess periods.

Statistics for Items 16-20 are included in Tables 12 and 13.

TABLE 12

MOTHERS' AND RESIDENTS' RATINGS OF ITEMS 16-20

	Item 16	Item 17	Item 18	Item 19	Item 20
Residents (N=36)					
Very Effective	1	5	3	3	4
Effective	22	20	4	22	27
Not Effective	2	3	5	2	0
Never Done	11	8	24	9	5
Mothers (N=30)					
Very Satisfied	4	3	2	2	4
Satisfied	9	5	3	8	10
Not Satisfied	14	13	20	17	15
Not Needed	3	9	5	3	1
Chi Square	20.45	15.39	21.42	21.21	25.14
p-value	<.001	<.01	<.001	<.001	<.001

TABLE 13

MOTHERS' AND RESIDENTS' SELECTIONS OF
IDEAL PROVIDERS FOR ITEMS 16-20

	Item 16	Item 17	Item 18	Item 19	Item 20
General Pediatrician					
Mothers	7	9	6	9	12
Residents	27	22	20	27	32
Asthma Specialist					
Mothers	17	14	14	18	14
Residents	1	--	--	--	2
Other					
Mothers	6	7	10	3	4
Residents	8	14	16	9	2
Chi Square	25.94	21.42	22.56	27.04	18.36
p-value	<.001	<.001	<.001	<.001	<.001

Discussion

Category 4: Information Related to School Care of Asthmatic Children

This area of study included five items related to specific information provided to mothers about how asthma affects their child in school. Behaviors studied in this section included residents' skills in talking with mothers about keeping asthma medications in school, determining if school personnel are able to provide necessary emergency care to asthmatic students, and discussing with mothers how the illness might affect the child's school performance and behavior.

Consistently high p-values of <.001 suggested statistical significance of differences between mothers' and residents' responses to items in this category. This set of questions appeared to reveal the most statistically significant discrepancies between mothers' satisfaction and residents' effectiveness.

Almost one-half of the mothers were not satisfied with their pediatrician's skills in talking with them about frequency of asthma attacks at school (Item 16), although 13 indicated satisfaction in this area. However, the majority of residents (23) stated that they were effective in providing this service and only 2 reported that they were not effective. Eleven residents had never discussed this topic with mothers.

Although 25 residents stated that they were effective when talking about keeping asthma medications at school (Item 17), only 8 mothers were satisfied with this service. Three residents indicated that they were not effective in this area, while 13 mothers were not satisfied.

Twenty-four residents stated that they had never talked with mothers about how well school personnel would be able to provide emergency care for a child during an asthma attack (Item 18), while 20 mothers indicated that they were not satisfied with this service. Only 7 residents felt effective in this area; 5 mothers were satisfied with this service. Responses to this item, with a p-value of <.001, had high statistical significance.

Although the majority of residents (25) stated that they were effective or very effective when discussing how asthma affects a child's school performance and behavior (Item 19), 17 mothers were not satisfied with this service. Only 2 residents felt that they were not effective in this area, while one-quarter had never talked about this topic with mothers. The difference between mothers' and residents' responses to this item was highly significant, with a p-value of <.001.

The majority of residents (31) stated that they were effective when talking with mothers about how asthma affects their child's physical activities at school (Item 20). Although 14 mothers were satisfied with this service, 15 were not satisfied with their pediatrician's skills in this area. A p-value of <.001 indicated that differences between participants' responses to this item were highly significant.

P-values for responses to "Ideal Provider" ratings for Items 16-20 were all <.001. The majority of residents stated that general pediatricians should provide each of the services described in this set of questions. Twenty-four residents had never talked with mothers about how well school personnel can provide emergency care for asthmatic children (Item 18); 16 stated that a social worker should provide this

service to mothers. One-third of the mothers indicated that social workers should discuss this topic with parents, although almost one-half preferred that an asthma specialist assume this responsibility. The majority of mothers (17) wanted specialists to talk with them about frequency of asthma attacks at school (Item 16); 18 wanted to talk with a specialist about how their child's school performance was affected by the illness (Item 19). Responses indicated that while 12 others expected to talk with a general pediatrician about how their child's physical activities at school should be or are restricted, almost one-half preferred to discuss this topic with a specialist. Only one mother did not need this service from her pediatrician.

Presentation of Mothers' Responses to Questions Regarding Ability of School Personnel to Provide Adequate Care to Asthmatic Children

Mothers were asked ten questions related to school care of asthmatic children. Responses to these items are presented in Table 14 and are summarized as follows.

Only 9 mothers stated that there was a full-time nurse at their child's school (Item 1). Almost all mothers (26) worried that their child would have an asthmatic attack while at school (Item 7). However, fewer than one-half of the mothers stated that their child has problems in school caused by asthma (Item 5).

The majority of mothers (25) expressed concern that their child's teacher should know more about the child's asthmatic condition (Item 6). All respondents felt that they were able to give information about

TABLE 14

MOTHERS' ATTITUDES TOWARD SCHOOL CARE OF ASTHMATIC CHILDREN

Item	Mothers' Responses (N=30) Agree	Disagree
1. There is a full-time school nurse who is able to take care of _____ in case she/he has an asthmatic attack during the school day.	9	21
2. _____'s teacher has called or written to me to ask about _____'s asthma.	12	18
3. I am able to explain things about _____'s asthma to teachers who might ask.	30	--
4. There are more things that I would like _____'s teachers to know about _____'s asthma.	23	7
5. Sometimes _____ has problems in school because of asthma.	12	18
6. Sometimes I wonder if _____'s teachers know everything they should about his/her asthma.	25	5
7. Sometimes I worry that _____ will have an asthmatic attack at school.	26	4
8. Teachers should ask me to tell them about _____'s health problems caused by asthma.	25	5
9. The teachers at _____'s school are interested in hearing my concerns about his/her asthma.	22	8
10. I should call or write to _____'s teachers to tell them what they need to know about his/her asthma.	25	5

asthma to teachers (Item 3), although more than three-quarters stated that they would like teachers to be more informed about their child's condition (Item 4).

Only 12 mothers reported that teachers had asked for information about the child's health problems (Item 2), although the majority of respondents (22) stated that teachers seemed interested in talking with mothers about concerns they have about their child's asthma (Item 9). Twenty-five mothers indicated that teachers should ask about their child's condition, while an equal number of respondents stated that mothers should be responsible for providing teachers with information about the child's health problems.

Presentation of Residents' Responses to Questions Regarding Working With Asthmatic Patients and Communication Training

Residents were asked four questions about providing health care to children and their parents, and four questions about receiving communication training. Results of their responses are presented in Tables 15 and 16 and are summarized as follows.

Although 14 residents indicated that working with parents of asthmatic children was not a satisfying experience (Item 1), the majority (22) agreed that they enjoyed working with this population. Only 2 residents did not feel competent in their work with parents of asthmatic children (Item 2), while 34 respondents agreed with this statement. All residents perceived that parents of asthmatic children related to them in a positive way (Item 3).

TABLE 15

RESIDENTS' ATTITUDES TOWARD WORKING WITH ASTHMATIC CHILDREN AND THEIR PARENTS

Item	Residents' Responses (N=36)			
	Strongly Agree	Agree	Disagree	Strongly Disagree
1. In general, working with parents of asthmatic children is a satisfying experience for me.	1	21	14	--
2. In general, I am competent in my work with parents of asthmatic children.	5	29	2	--
3. In general, I think that parents of asthmatic children respond to me in a positive way.	5	31	--	--
4. In general, working with asthmatic children is a satisfying experience for me.	2	20	13	1

TABLE 16

RESIDENTS' ATTITUDES TOWARD COMMUNICATION TRAINING

Item	Residents' Responses (N=36) Strongly Agree	Agree	Disagree	Strongly Disagree
5. I would find it helpful to receive some training for communicating with parents of chronically ill children.	12	20	4	--
6. Medical schools should provide elective parent-pediatrician communication training for students who are entering pediatric residencies.	8	23	5	--
7. There are people in the Department of Pediatrics whom I can consult if I have a question about how to work with parents of asthmatic children.	15	21	--	--
8. As a medical student, I received training for communicating with parents.	3	11	18	4

Only 2 residents strongly agreed that working with asthmatic children was satisfying (Item 4), although more than one-half agreed with this statement. Thirteen stated that taking care of asthma patients was not satisfying, and one respondent strongly disagreed with this item.

The majority of residents (22) did not receive training for communicating with parents while in medical school (Item 8). Thirty-one respondents agreed that medical students who are planning to become pediatricians should be able to take elective courses in communicating with parents (Item 6). Thirty-two indicated that they would like to receive training for communicating with parents of chronically ill children during their residency program (Item 5). All residents stated that there are health care professionals in the Department of Pediatrics at Jacobi Hospital who are available to talk about how to work with parents of asthmatic children (Item 7).

Statistical analysis of all data has been presented in this chapter. In the next and final section, Chapter V, data are discussed in relation to the five questions guiding the study as outlined in Chapter I.

CHAPTER V

SUMMARY, DISCUSSION, AND IMPLICATIONS FOR FURTHER RESEARCH AND TRAINING

The last chapter includes a summary and discussion of results obtained in the study. Results have been interpreted to provide possible answers to the five questions guiding the study, as outlined in Chapter I. Conclusions and implications for further research and training are presented.

Summary

Thirty mothers whose school-aged children were treated at Jacobi Hospital, Bronx Municipal Hospital Center, were asked to rate the quality of support and information they received from their child's pediatrician. Thirty-six pediatric resident physicians in the same setting were asked to rate their effectiveness in providing these services to parents of asthmatic children.

The researcher developed a list of twenty specific behaviors related to support and information which were rated by participants. Interviewer-administered questionnaires were developed and pilot-tested by the researcher. Data were analyzed to identify possible differences between mothers' and residents' ratings and self-ratings. Results were interpreted to provide answers to the five questions guiding the study.

Discussion of Participants' Responses to Questionnaire Items

The major purpose of this study was to determine if there is a need to provide training programs which would enable pediatric residents to improve communication skills with parents of asthmatic children. Five questions, which were outlined in Chapter I, guided the study. Mothers' and residents' responses, including anecdotal comments, are presented here in a discussion of these five questions.

1. To What Extent Do Mothers of School-Aged Children Treated at Bronx Municipal Hospital Center Feel That They Are Receiving Adequate Support and Information From Their Child's Physician?

Mothers who participated in this study appeared to be generally satisfied with the quality of emotional support they received from pediatricians at Jacobi Hospital. The researcher observed that most mothers did not make additional comments about support services when responding to these items. However, one mother expressed concern about medical expenses: "We have no Medicaid and they charge me and we have a problem." Another mother described her frustrations with a landlord who refused to turn the heat up in her apartment building: "I have to fight the landlord alone. Everyone is cold, but no one is willing to speak up. I'm doing this all alone--but it's for my child." This mother stated that her child's asthma attacks had become worse since they had moved into their new apartment.

One mother claimed that she had severe emotional problems caused by her child's asthma: "I can't even get a job because he's sick all the time. I've had nervous breakdowns because of all this." This mother

reported that she had found her ten-year-old son smoking the night before the interview took place. She had made her son walk "about two miles" with her to the hospital when his asthma attack began, "to teach him a good lesson." When the researcher asked these three mothers if they had talked to their pediatricians about their problems, each mother stated that she had not. Reasons included: "What can they (pediatricians) do?" and "I just put up with it."

Several residents commented that the majority of mothers they met in their clinics did not discuss worries or concerns during appointments. One resident stated, "Mothers will rarely say they're worried. You see so many single mothers--with no support systems, no one to help them. I don't discuss things with them; I just get impressions. Some of them (mothers) are fine--some of them are so anxious."

Stein et al. (1979) reported that only 25% of the one-hundred mothers interviewed in their 1978 study indicated that they received support from health care professionals at Jacobi Hospital. These researchers suggested that mothers most often depend on friends and relatives to provide support. Many mothers in this study may have received support from non-medical sources, as suggested by Stein et al.

Responses indicated that the majority of mothers were satisfied with the quality of support services they received. Differences between results obtained in this study and results obtained by Stein et al. may be explained by two factors. First, Stein et al. asked mothers only if they were receiving general support services; mothers in this study were asked to assign satisfaction ratings to five specific items related to support. Secondly, mothers in this study had children who, although

chronically ill, were not physically handicapped and were able to attend regular schools. Mothers interviewed by Stein et al. had children with more severe chronic and handicapping conditions, and may have had greater needs for support services.

The majority of mothers were satisfied with the way pediatricians answered their questions. However, responses to other items related to education indicated that mothers were not satisfied with the quality of information they received. One mother reported that she was unable to explain medical procedures to her son because she did not receive information from the pediatrician about treatments: "I'd like more information, especially when they give him needles. He asks me what they're doing and I don't know what to say. I haven't asked--I guess I should."

One mother stated that she was able to ask questions during clinic appointments, but was critical of the information she received in the emergency room: "Every time he goes to the emergency room, he sees someone different. I've been through this so many times. They come in and don't look at you, don't talk to you, then leave--and you don't even know what's going on." Other mothers made similar comments: "I come over here (Jacobi Hospital) and they don't say nothing to me. I worry about him. They don't let me know things." Another mother stated: "In the emergency room they come in and don't look at you--they talk, then disappear. If you have a question, you have no one to talk to." In general, mothers' needs for more adequate information were greatest in the emergency room.

One mother indicated that she received conflicting information about her child's health problems from different providers: "In the clinic, my

kid sees a different doctor every time. There's no follow-through. The specialist says one thing, the pediatrician says another. I wish that we could get together, all of us at the same time--with me there."

Twelve mothers stated that they would like more information about what to do when their child has an asthmatic attack at home. The majority of mothers reported that they understood how to give preventive medications. However, a significant number of mothers indicated that they would like more information about school care of asthmatic children. More than one-half of the mothers did not receive adequate information from pediatricians about how asthma might affect their child's school performance and ability to learn. Several mothers mentioned that they would like to know how asthma medications might affect their child's behavior, especially at school. Responses to school-related items consistently suggested that mothers would like to talk more with pediatricians about how asthma and asthma medications affected their child's school work and behavior.

The majority of mothers indicated that they would like to receive written materials about asthma. Although most respondents depended on health care workers for information about their child's illness, several mothers stated that they tried to locate materials in magazines and newspapers: "I know about asthma because I read stuff myself--I look for it (information) in magazines."

Stein et al. reported that 78% of the mothers in their study stated that they received information about their child's chronic condition. Results of this study indicated that the majority of mothers would like to receive more information, especially educational materials. In

addition, they would like to receive consistent information about their child's health problems from the various providers whom they see at Jacobi Hospital.

2. To What Extent Do Pediatric Resident Physicians at Bronx Municipal Hospital Center Perceive Themselves to Be Effective in Providing Information and Support to Mothers of School-Aged Asthmatic Children?

In general, residents interviewed in this study indicated that they were effective in most areas related to providing emotional support. More than one-third reported that they had never helped mothers identify non-medical sources of support to help them cope with their child's illness (Item 5). Several residents commented that they had never thought of doing this with mothers. One respondent suggested that pediatric nurse-practitioners organize and run support groups for parents at Jacobi Hospital.

Residents repeatedly mentioned that heavy work loads limited the amount of time they had to spend with families: "I wish I had more time to spend with parents. There's a big different between having time and spending time." Another resident said, "I don't tell parents to call me if they want to talk or ask me something--I wouldn't have the time to talk on the phone."

Several respondents stated that they did not tell parents to call them at the hospital because there is no effective way that residents can be reached: "I just tell parents that Wednesday is my clinic day, and to come find me here. I'm all over the hospital and there's not a good way to reach me. This hospital is set up horribly for parents to get in touch with us. That's why they keep going to the E.R. (emergency

room)."

Physicians at Jacobi Hospital wear electronic pagers or "beepers." In order to contact a physician at the hospital, one must dial a seven-digit number which activates the electronic beeper. Each beeper has a different number, so it is impossible to "beep" a physician unless the caller knows the correct beeper number. Residents at Jacobi Hospital received a different beeper and new number each time they began new rotations. Consequently, they had new beeper numbers every four weeks. One respondent suggested that residents wear the same electronic beeper for three years so that it would be easier for parents to call their pediatricians.

Residents indicated that it was difficult to reassure mothers who did not speak or understand English. One resident remarked that although translators were available in the ambulatory care clinic, it was sometimes impossible to locate a translator in the emergency room.

In general, lack of time and language barriers were most often cited as factors which prevented residents from providing more emotional support for parents of asthmatic patients. Although respondents reported that they were generally effective in providing support services, anecdotal comments made during interviews suggested that a significant number of residents would like to be more effective in this area.

Most residents reported that they were effective in providing general information about asthma to parents. However, several respondents stated that it was difficult to tell parents how long their child's illness might last: "How should I know? I'll tell them (parents) and

they won't believe me, or I'll be wrong and they will believe me."

Time constraints were frequently mentioned by residents when they reponded to items about providing information: "Time--we need more time. A lot of parents need information and you need about a half-hour with them. You have to keep repeating the information so they'll understand you."

The majority of residents stated that non-compliance was the most frustrating factor related to providing health care to asthmatic children: "I wish parents would give the meds (medications)--before the attack. Compliance--it's so frustrating. I'd like to get parents to understand how important it is for them to give their kids medicines." Several residents stated that non-compliance on the part of parents usually resulted in unnecessary emergency room visits and hospitalizations: "They (parents) don't give the kids the meds--they just keep bringing them back to the E.R. when they can't breathe." Respondents seemed to agree that parents need more information about how to administer medications and how to prevent attacks.

More than one-half of the respondents stated that they would like to have access to educational materials to give to parents: "We need hand-outs and someone who could spend a lot of time explaining this illness--to the parent and to the kid." Although many residents agreed that parents should receive written information, one respondent questioned the value of providing materials: "They (written materials) wouldn't be used if you gave them away, not understood if they were used--and parents wouldn't use them even if they could understand them."

Most residents indicated that they were effective in providing information about home care of asthmatic children. However, many respondents mentioned that home episodes of asthma could be prevented if parents administered proper dosages of medications: "They (parents) stop giving the meds when the kid stops wheezing. They've got the meds right in the house, but they don't give them." Several residents stated that some parents did not appear to understand that their children must take medications to prevent attacks: "Some of my parents don't want to believe that you can prevent an attack. They have preconceived ideas and resist what you tell them about drugs. They don't use them, then they go to the E.R." Several residents made comments which suggested that they did not usually discuss school care of asthmatic children with parents: "I haven't thought of doing these things--you kind of forget where else kids go when they're not in the hospital." One resident stated that she assumed that "mothers do all those things with the teachers," while another resident reported that he discussed school-related issues "only when the kid has been out (of school) a lot." Although responses indicated that residents discussed school care with parents, anecdotal records suggested that most respondents did not talk about how well a child's classroom teacher would be able to provide emergency care during an asthmatic episode.

In general, residents appeared to feel that although they were effective in providing information, they would like to spend more time educating parents about medications and prevention of asthma attacks. Time constraints and language barriers were the most commonly mentioned problems related to giving parents information. The majority of

residents stated that non-compliance was the major problem caused by parents' lack of information.

3. To What Extent Do Mothers of School-Aged Asthmatic Children and Pediatric Residents Agree That Pediatricians Are the Most Appropriate Health Care Professionals to Provide Information and Support?

In general, a significant number of mothers indicated that they would prefer to receive information and support from asthma specialists, while a significant number of residents reported that a general pediatrician was the "Ideal Provider" for most services related to information and support. Most residents seemed to believe that many of their asthma patients would have fewer acute episodes if parents administered correct dosages of medications. One resident stated that only patients with severe forms of asthma should be treated by specialists: "Asthma is a disease that a general pediatrician should handle--I don't think a specialist is necessary, except in special, bad cases." However, a significant number of mothers consistently indicated that they would prefer to receive information and support services from specialists. More than three-quarters of the mothers wanted to talk with a specialist about worries and concerns they have about their child's illness; two-thirds wanted to have a specialist answer questions about their child's condition. Eighteen mothers stated that they would like to discuss school-care issues with a specialist. In addition, the majority of mothers indicated that they would like a specialist to give them information about allergens which may precipitate attacks.

Mothers may have repeatedly identified asthma specialist as the "Ideal Provider" for many items because they believe that a specialist

would be more knowledgeable, competent, and understanding. However, the researcher did not probe mothers' responses to "Ideal Provider" questions and did not, therefore, obtain data to explain respondents' choices. The researcher's general impressions were that residents did not consider asthma to be a life-threatening illness, especially if parents complied with physicians' instructions for prophylactic medications. The majority of residents mentioned that they did not have enough time in the emergency room or in clinics to educate parents about asthma medications. Parents may believe that specialists have more time to spend with patients and families.

In general, mothers and residents did not agree that general pediatricians are the most appropriate health care professionals to provide information and support to parents.

4. To What Extent Do Mothers of School-Aged Asthmatic Children Feel Effective in Providing Teachers With Information About Their Child's Illness?

All mothers interviewed in this study reported that they were able to provide teachers with information about their child's illness. However, a majority of mothers stated that teachers should know more about their child's health problems caused by asthma. Some respondents believed that mothers were responsible for providing teachers with information; other mothers felt that teachers should also ask parents about children's health problems. Fewer than one half of the mothers reported that teachers had contacted them for information about their child's asthma.

One mother stated: "Teachers take your kid's asthma more seriously if they hear about it from a doctor." Other mothers reported that teachers seemed to view asthma exclusively as an emotional problem rather than as a medical condition: "The teachers say, 'It's psychological--get it off your mind.' It's better for a doctor to call and tell them (teachers) things--they don't believe parents. It would be good if hospitals and schools could work together."

Mothers' responses indicated that they feel generally competent in talking with teachers about their child's health problems, but one mother stated that she would like to have written materials to give to her son's teachers: "If I had some books or something like that--it would help her (the teacher) learn more, and it would help my son."

In general, mothers felt effective in providing information about asthma to teachers. Several mothers reported that teachers often think that asthma is an emotional illness. These mothers indicated that although they were able to explain their child's illness to teachers, school personnel and pediatricians should have more frequent communication.

5. To What Extent Do Pediatric Residents at Bronx Municipal Hospital Center Agree That Communication Training Would Improve Their Skills in Providing Information and Support to Parents of Children With Asthma?

The majority of residents agreed that training would improve their skills in communicating with parents of asthmatic children. In addition, 31 respondents felt that medical students who are planning to become pediatricians should be able to take elective courses to learn how to communicate with parents. Residents seemed to generally agree that this

type of training would be useful to both medical students and resident pediatricians. More than one-half of the respondents had not received communication training in medical school.

Residents' general attitudes toward working with asthmatic patients and their parents were also studied. More than one-third of the respondents disagreed that providing health care to asthmatic children was a satisfying experience. Fourteen disagreed that working with parents of asthmatic children was a satisfying experience. Residents' anecdotal comments suggested that parents' non-compliance significantly affected residents' attitudes toward working with asthma patients. However, the degree to which residents' attitudes affected their skills in providing information and support was not measured in this study.

Residents identified a variety of communication-related topics which they would like to learn more about: "I'd like to learn more about how to explain things to parents--how to help them deal with their kid's illness in the outside world." Another resident stated that pediatricians should know more about the care of children in non-medical settings: "I think we could learn more about some of the things you mentioned--like how to teach parents--and what kids need at home and in school, and who takes care of them."

Several residents mentioned that they would like to know more about their patients' cultures and lifestyles: "I try to place myself outside the hospital--I'm unaware of their lifestyles. I wish I knew more about the culture of this population--that I spoke Spanish. Then I'd be able to tell them how important health is."

One resident suggested that pediatricians receive training for communicating with parents of children with a wide range of chronic illnesses: "There should be a communication conference here--not just directed at asthma, but at diabetes--at all chronic illnesses."

Results indicated that a majority of residents in this setting would be interested in receiving training to improve their skills in giving support and information to parents. In addition, anecdotal comments revealed that several respondents have already identified specific areas related to communication which they would like to know more about.

Conclusions

The following conclusions have been made based on the researcher's interpretation of results:

1. Mothers who participated in the study were generally satisfied with the quality of support and information they received from pediatricians at Jacobi Hospital. However, a significant number of respondents indicated that they would like more information from pediatricians about effects of asthma and asthma medications on their child's school performance and behavior.
2. Pediatric residents at Jacobi Hospital generally felt effective in providing information and support to mothers of school-aged asthmatic children. However, the majority of residents reported that the quality of their work with parents was often

adversely affected by two factors. First, language barriers frequently prevented residents from communicating effectively with Hispanic parents. Secondly, heavy work loads in the emergency room and clinics significantly reduced the amount of time residents had to spend teaching parents and answering questions.

3. Non-compliance was identified by many residents as a serious problem caused by parents not knowing how to provide adequate home care to asthmatic children.
4. Mothers and pediatric residents generally disagreed about who was the most appropriate health care professional to provide information and support. Mothers consistently identified asthma specialists as the "Ideal Provider," while residents usually indicated that asthma patients, in most cases, could be cared for by general pediatricians.
5. All mothers in the study reported that they were able to provide information about their child's illness to teachers. However, several mothers revealed their perceptions that teachers often view asthma as an emotionally caused illness rather than as a potentially serious medical condition. Anecdotal comments suggested that mothers would like pediatricians to assume more responsibility for providing teachers

with information about students' health problems.

6. Pediatric residents at Jacobi Hospital indicated an interest in receiving further training related to communication with parents of asthmatic children. Respondents generally supported the idea of including communication courses in medical schools and residency programs.

Implications for Further Research

One of the major limitations of this study was that data were obtained from only 30 mothers and 36 residents. Replication of the study with samples of at least 100 mothers and 100 pediatricians is recommended. Data from larger samples would enable researchers to study possible effects of specific variables on mothers' ratings. Variables such as financial status, ethnicity, number of children, number of other relatives with asthma, educational background, and type of medical insurance could be studied. Effects of pediatricians' general attitudes toward chronicity on communication skills could be measured. In addition, pediatricians who are Spanish-speaking and who have had previous communication training could be included in a larger sample. Probes of mothers' and pediatric residents' choices of "Ideal Providers" might provide significant findings which could be used to plan communication training programs for health workers. In general, larger samples would allow for more in-depth analysis of data.

A significant number of mothers indicated that they would like more information about the management of childhood asthma. Respondents generally agreed that they would like to receive written materials, such as pamphlets and books, about their child's illness. Research related to effects of patient education on parents' compliance behaviors is recommended. As part of this study, patterns of parents' use of emergency room services for asthma treatments could be studied in relation to the amount of patient education they received from health care professionals. Effects of support groups for parents on children's health status and parents' compliance behaviors could also be evaluated.

Mothers consistently suggested that teachers' perceptions of the etiology of asthma are often incorrect. An investigation of a sample of classroom teachers' knowledge of asthma and general attitudes toward asthmatic students is recommended. The proposed study should be constructed to measure teachers' perceptions of the validity of parents' information and instructions regarding school care of asthmatic students. Teachers' preferences for receiving information from parents or from health care workers could be surveyed. Results of this study might suggest that teacher education programs include information about the needs of asthmatic children who attend regular schools. In addition, results might indicate how parents, teachers, pediatricians, and other health care professionals can collaborate in the care of children with a variety of common pediatric illnesses, including cystic fibrosis, diabetes, and cancer.

In general, further research related to the study described in this dissertation should include larger samples of parents, teachers, and

health care workers. In addition, non-English-speaking mothers whose children are cared for by professionals in schools and health care settings should be included in any further research related to parent-pediatrician communication.

Implications for Training

Results of the study and respondents' anecdotal comments suggested that training programs for medical students, pediatricians, classroom teachers, and parents would be useful. General recommendations for training courses are described below.

1. Communication courses are currently taught in the majority of medical schools in the United States (Werner et al., 1979). Courses related specifically to parent-pediatrician communication are recommended for medical students and pediatric resident physicians. Content of communication courses should include information about the culture and lifestyles of specific patient populations. Such courses would be most appropriate for medical students and residents who are working in inner-city health settings with large non-white patient populations. Family structures, general attitudes toward health and illness which affect compliance, and non-traditional "folk medicine" practices should be discussed. Effects of chronic illness and hospitalization on children, parents, and families should be studied.

Participants in communication courses should view videotapes of their interactions with patients and parents with instructors who can provide specific recommendations about students' communication skills. Finally, communication courses should include discussions about how pediatricians can improve parents' compliant behaviors. Parent-pediatrician communication courses should follow guidelines recommended by members of the Task Force on Pediatric Education.

2. Mothers' responses and anecdotal comments suggested that elementary classroom teachers might benefit from training related to school care of asthmatic children. Content of programs for teachers should include information about the etiology of asthma, effects of asthma and asthma medications on children's school performance and behavior, and how to provide adequate emergency care to a child who suddenly suffers an attack at school. Teachers should be trained to listen objectively to parents' information about students' health problems. Effects of other chronic childhood diseases, such as diabetes and cystic fibrosis, should be explained to teachers. The proposed course would be appropriate for both preservice and inservice teachers. A needs assessment should be conducted to determine

specific needs and interests of participants. The desired outcome of the proposed course is that teachers and parents would be able to collaborate in the care and education of children with chronic illnesses.

3. Mothers' and residents' responses indicated that educational programs and support groups might improve parents' compliant behaviors. Courses for parents should include information about home and school management of childhood asthma. Health education materials, such as films and books, should be used for instruction. Classes could be taught by pediatric nurse-practitioners who have been trained as patient educators. Information presented to parents in classes would be reinforced by pediatricians during clinic visits. Classes should be designed to include opportunities for parents to receive support from instructors and peers. Discussions about problems caused by raising a child with a chronic illness should be planned. A combination of information and support should be provided. The proposed course might improve parents' skills in preventing and controlling their child's asthma attacks. Non-compliance, which often results in preventable emergency room visits and hospitalizations, might be reduced.

Conclusion

There are at least two possible conclusions one can make after reading this report. The first conclusion, which is based on a review of statistics presented in Chapter IV, is that most mothers of asthmatic children received adequate support and information and that pediatric residents were generally effective in providing these services.

However, readers who, after reviewing data sets, give equal consideration to anecdotal comments included in the text might conclude that there are serious flaws in the quality of care provided to mothers whose children are treated at Jacobi Hospital.

Pediatric residents frequently talked about their frustrations with non-compliant parents of asthmatic children. Most residents did not have the time, skills, or resources to teach parents how to control their child's illness. Consequently, many mothers left the hospital not understanding how to prevent future asthmatic episodes. Children, parents, and pediatricians were all victims in this complex situation.

Results of the study indicated that there is clearly a need to train pediatricians, mothers, and teachers. However, education will not solve all problems encountered by residents and mothers in this setting. The hospital administration must attempt to improve physicians' work loads, especially in clinics and the emergency room, so that residents can spend more time with children and parents. The hospital environment must be safer for patients. It is ironic and alarming that in a

nation which trains physicians to perform complicated medical procedures, children are cared for in hospitals with broken windows and shards of glass on the floor.

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APPENDICES

APPENDIX A

PILOT TEST OF INSTRUMENT

PART 1

Directions: After you read each item, circle the most appropriate number which indicates how important you feel it is for pediatricians to . . .

Choices:

1. Always Important
2. Usually Important
3. Occasionally Important
4. Never Important

1.	Ask mothers to identify others who need information about their child's illness (e.g., spouse, teachers, live-in relatives, etc.).	1	2	3	4
2.	Explain why medications are being prescribed.	1	2	3	4
3.	Ask mothers questions about what you have discussed in order to determine how accurately they have understood information you have presented.	1	2	3	4
4.	Ask mothers if there is anything that is worrying them about their child's illness.	1	2	3	4
5.	Encourage mothers to contact you if they have special concerns or problems that may arise before the next scheduled appointment.	1	2	3	4
6.	Assess mothers' present level of knowledge about their child's illness (e.g., possible causes of asthma, treatment, prevention, etc.).	1	2	3	4
7.	Discuss how to control environmental factors which may trigger attacks (e.g., diet, dust, etc.).	1	2	3	4
8.	Ask mothers if they have understood your explanations of medical facts.	1	2	3	4
9.	Reassure mothers with truthful statements when they become upset.	1	2	3	4

10.	Ask mothers if they have further questions or problems to discuss before the appointment is over.	1	2	3	4
11.	Ask mothers about prior experiences with their child's asthma (e.g., when attacks begin, who is around to help during attacks, etc.).	1	2	3	4
12.	Discuss the care of the asthmatic child in language that mothers are able to understand.	1	2	3	4
13.	Ask mothers to repeat information back to you in order to determine how accurately they have understood information being discussed.	1	2	3	4
14.	Ask mothers to tell you why they are upset.	1	2	3	4
15.	Provide mothers with additional materials related to caring for an asthmatic child (e.g., pamphlets, articles, directions for medications, etc.).	1	2	3	4
16.	Ask mothers to describe the quality of care available to their child if or when s/he has an attack at school.	1	2	3	4
17.	Discuss possible side effects of medication.	1	2	3	4
18.	Ask mothers if they have questions related to the information being discussed.	1	2	3	4
19.	Give mothers time to think about information before making decisions related to caring for their asthmatic child.	1	2	3	4
20.	Summarize, at the end of your time together, the most important points you have discussed during your meeting.	1	2	3	4

21.	Ask mothers how often attacks occur while the child is at school.	1	2	3	4
22.	Discuss the prevention of asthma in language that mothers are able to understand.	1	2	3	4
23.	Suggest possible questions related to your discussion when mothers do not ask anything.	1	2	3	4
24.	Ask mothers to identify specific concerns they may have about their child's illness (e.g., costs of medical care, effects of illness on family members, etc.).	1	2	3	4
25.	Explain how to administer medications.	1	2	3	4
26.	Provide additional opportunities for mothers to talk with you about things that upset them regarding their child's illness.	1	2	3	4
27.	Discuss the causes of asthma in language that mothers are able to understand.	1	2	3	4
28.	Ask mothers to identify strategies for coping with problems caused by their child's illness (e.g., talk to a friend, arrange for someone to help with care of the child, etc.).	1	2	3	4

PART 2

Please complete the following questions as indicated:

A. What do you think are your three greatest strengths in working with parents of asthmatic children? Please list them briefly below:

(1) _____

(2) _____

(3) _____

B. What do you think are your three greatest problems in working with parents of asthmatic children? Please list them briefly below:

(1) _____

(2) _____

(3) _____

C. What are three areas related to working with parents of asthmatic children in which you would like to become more competent? Please list them briefly below:

(1) _____

(2) _____

(3) _____

Please check the most appropriate response to the following statements:

Choices:

1. Strongly Agree
2. Agree
3. Disagree
4. Strongly Disagree

D. In general, I enjoy working with parents of asthmatic children very much.	1	2	3	4
E. In general, I am very competent in my work with parents of asthmatic children.	1	2	3	4

F. In general, I think that parents of asthmatic children respond to me in a positive way. 1 2 3 4

PART 3

Directions: After you read each item, circle the most appropriate number which indicates your present ability to . . .

Choices:

1. Excellent
2. Good
3. Average
4. Poor
5. Unaware of Behavior; Have Not Done
6. Aware of Behavior But Have Not Done

1.	Ask mothers to identify others who need information about their child's illness (e.g., spouse, teachers, live-in relatives, etc.).	1	2	3	4	5	6
2.	Explain why medications are being prescribed.	1	2	3	4	5	6
3.	Ask mothers questions about what you have discussed in order to determine how accurately they have understood information you have presented.	1	2	3	4	5	6
4.	Ask mothers if there is anything that is worrying them about their child's illness.	1	2	3	4	5	6
5.	Encourage mothers to contact you if they have special concerns or problems that may arise before the next scheduled appointment.	1	2	3	4	5	6
6.	Assess mothers' present level of knowledge about their child's illness (e.g., possible cause of asthma, treatment, prevention, etc.).	1	2	3	4	5	6
7.	Discuss how to control environmental factors which may trigger attacks (e.g., diet, dust, etc.).	1	2	3	4	5	6
8.	Ask mothers if they have understood your explanations of medical facts.	1	2	3	4	5	6

9.	Reassure mothers with truthful statements when they become upset.	1	2	3	4	5	6
10.	Ask mothers if they have further questions or problems to discuss before appointment is over.	1	2	3	4	5	6
11.	Ask mothers about prior experiences with their child's asthma (e.g., when attacks began, who is around to help during attacks, etc.).	1	2	3	4	5	6
12.	Discuss the care of the asthmatic child in language that mothers are able to understand.	1	2	3	4	5	6
13.	Ask mothers to repeat information back to you in order to determine how accurately they have understood information being discussed.	1	2	3	4	5	6
14.	Ask mothers to tell you why they are upset.	1	2	3	4	5	6
15.	Provide mothers with additional materials related to caring for an asthmatic child (e.g., pamphlets, articles, directions for medications, etc.).	1	2	3	4	5	6
16.	Ask mothers to describe the quality of care available to their child if or when s/he has an attack at school.	1	2	3	4	5	6
17.	Discuss possible side effects of medication.	1	2	3	4	5	6
18.	Ask mothers if they have questions related to the information being discussed.	1	2	3	4	5	6
19.	Give mothers time to think about information before making decisions related to caring for their asthmatic child.	1	2	3	4	5	6
20.	Summarize, at the end of your time together, the most important points you have discussed during your meeting.	1	2	3	4	5	6

21.	Ask mothers how often attacks occur while the child is at school.	1	2	3	4	5	6
22.	Discuss the prevention of asthma in language that mothers are able to understand.	1	2	3	4	5	6
23.	Suggest possible questions related to your discussion when mothers do not ask anything.	1	2	3	4	5	6
24.	Ask mothers to identify specific concerns they may have about their child's illness (e.g., costs of medical care, effects of illness on family members, etc.).	1	2	3	4	5	6
25.	Explain how to administer medications.	1	2	3	4	5	6
26.	Provide additional opportunities for mothers to talk with you about things that upset them regarding their child's illness.	1	2	3	4	5	6
27.	Discuss the causes of asthma in language that mothers are able to understand.	1	2	3	4	5	6
28.	Ask mothers to identify strategies for coping with problems caused by their child's illness (e.g., talk to a friend, arrange for someone to help with care of the child, etc.).	1	2	3	4	5	6

APPENDIX B

REVISED LIST OF TWENTY BEHAVIORS REVIEWED BY PEDIATRIC NURSE-PRACTITIONERS

1. Talking with mothers about things that worry them about their child's asthma.

2. Encouraging mothers to call you when they have a problem or concern about their child's asthma.

3. Reassuring mothers when they become upset when talking about their child's asthma.

4. Discussing specific problems or concerns mothers have about their child's asthma.

5. Helping mothers think of other people, like friends or relatives, who could help with them deal with problems caused by their child's asthma.

6. Answering mothers' questions about their child's asthma.

7. Explaining to mothers how asthma will affect their child in the next few years.

8. Discussing with mothers how many months or years their child's asthma is expected to last.

9. Helping mothers think of other people who might need to know about their child's asthma, like friends or relatives who live with them or spend a lot of time with their child.

10. Giving mothers materials, like books or pamphlets, which explain how to take care of a child with asthma.

11. Explaining to mothers what to do if their child has an asthmatic attack at home.

12. Explaining to mothers how their child's asthma medicine helps him/her.

13. Explaining to mothers how to give asthma medicine.

14. Talking with mothers about how well other people in their household can take care of their child during an asthmatic attack.

15. Explaining to mothers how to control certain things which might cause their child's asthmatic attacks, like dust or certain foods.

16. Talking with mothers about how often their child has asthmatic attacks during the school day.

17. Talking with mothers about keeping their child's asthma medicine in school in case of an asthmatic attack.

18. Talking with mothers about how well their child's teachers would be able to take care of their child during an asthmatic attack.

19. Discussing how asthma affects their child's ability to learn and do school work.

20. Talking with mothers about how asthma restricts their child's physical activities at home, or in school gym classes and recess periods.

APPENDIX C

LETTER AND EVALUATION FORM SENT TO PEDIATRIC NURSE-PRACTITIONERS

ALBERT EINSTEIN COLLEGE OF MEDICINE
of YESHIVA UNIVERSITY

MEMORANDUM

TO: Pediatric Nurse Practitioners DATE: October 22, 1981

FROM: Nadia Jensen

SUBJECT: Review of Behaviors List

I am a graduate student in the School of Education at the University of Massachusetts in Amherst. In a few weeks I will begin to collect data for my dissertation. I plan to interview 36 pediatric residents and 36 mothers of school-age asthmatic children. Residents will be asked to self-report how effective they are in providing support and information to mothers. Mothers will be asked to rate their child's doctor's skills in giving support and information. Residents and mothers will also be asked to identify the "ideal provider" who would be the most appropriate person to provide information and support. Mothers will be asked an additional set of questions related to the quality of health care available at their child's school. Data will be analyzed to measure possible differences (1) between mothers' and pediatricians' responses, and (2) among responses given by PL-1's, PL-2's, and PL-3's.

Although my committee at UMass has approved the questionnaire, they suggested that I show sections of the instrument to health professionals who work closely with mothers at Jacobi Hospital. I hope that you will have some time in the next few days to look over the list of behaviors I plan to use during interviews. Some questions I have about items include:

1. Will mothers be able to understand each statement?
2. Which items on the list are irrelevant or repetitive?
3. Are there any items related to giving information to asthmatic children's parents which should be added to the list?
4. How could the sequence of questions be improved?
5. In what ways could this questionnaire be improved?

I will appreciate any suggestions you have about language, sequence, or other aspects of this list. Please feel free to write your ideas on the form itself, or you can use the reaction sheet to write your comments.

If you have any questions about the study, please call me (Work Number: 430-8373 or Home Number: 822-4943) or look for me in the Clinic. Please return the list and reaction sheet to Jackie Kopet by Friday, October 30, 1981.

Thank you very much for spending time looking at the list!

TO: Pediatric Nurse Practitioners

REACTION SHEET

(Please return to Jackie Kopet by Friday, October 30, 1981)

1. Please list any suggestions you have about the list:

2. What do you dislike about the list?

3. What do you like about the list?

THANK YOU FOR COMPLETING THIS SHEET!

APPENDIX D

MATERIALS SENT TO CLINICAL INVESTIGATIONS COMMITTEE AT THE ALBERT EINSTEIN COLLEGE OF MEDICINE

ALBERT EINSTEIN COLLEGE OF MEDICINE
OF YESHIVA UNIVERSITY
1300 MORRIS PARK AVENUE, BRONX, N Y 10461 • CABLE EINCOLLMED, N Y

DEPARTMENT OF PEDIATRICS
Pediatric Ambulatory Care Division

Mailing Address
Bronx Municipal Hospital Center
Jacobi Hospital
Pelham Pkwy & Eastchester Rd
Bronx, New York 10461

November 16, 1981

Dear Dr. Cohen:

I am a graduate student in the School of Education, University of Massachusetts/Amherst. Since March, 1981, I have been at Jacobi Hospital working on my dissertation. I have also been working half-time for Ruth Stein and Dorothy Jessop as an interviewer for the Functional Status II study.

I am submitting for your signature a copy of the proposal which will be sent to the Committee for Clinical Investigations. The next meeting is scheduled for November 30, 1981, and all proposal materials must be sent to their office by November 18, 1981.

I am planning to interview 36 pediatric residents and 36 mothers of asthmatic children admitted to Jacobi Hospital. I expect that it will take six to eight weeks to complete all interviews. Ruth Stein has agreed to sponsor the study.

Please contact me if you have any questions about the proposal. I will be glad to answer any questions or hear any suggestions you may have. I can be contacted at 430-8373.

Thank you very much for your help.

Sincerely,

Nadia Jensen

ALBERT EINSTEIN COLLEGE OF MEDICINE - BRONX MUNICIPAL HOSPITAL CENTER
HOSPITAL OF THE ALBERT EINSTEIN COLLEGE OF MEDICINE

COMMITTEE ON CLINICAL INVESTIGATIONS
(INSTITUTIONAL REVIEW BOARD)

RESEARCH PROPOSAL

CCI NO.

Name of Principal Investigator Ruth Stein, M.D.	
Address Room 1N20, Jacobi Hospital	Telephone 212-430-5301
Dept., Division, or Service Department of Pediatrics, Pediatric Ambulatory Care Division	
Appointment (AECOM) (HAECOM) (BMHC) Associate Professor of Pediatrics	
Names of Collaborators Nadia Jensen	Departments and Appointments Research Assistant, Dept. of Pediatrics

Title of Proposal "Quality of Support Services Provided to Parents of Asthmatic Children at BMHC as Perceived by Mothers and Pediatric Residents"

Brief Summary of Proposal

The proposed study involves interviewing 36 pediatric residents and 36 mothers of school-aged asthmatic children treated at Jacobi Hospital. Data will be analyzed to measure possible differences in perceptions of quality of services provided in the following areas: 1) general advice, 2) support, 3) information related to caring for asthmatic children at home, and 4) information related to caring for asthmatic children at school.

Residents will be asked to self-report how effective they are in providing support, advice, and information to mothers. Mothers will be asked to rate thier child's doctor's skills in giving support, advice, and information. Residents and mothers will also be asked to identify the 'ideal' provider who would be the most appropriate person to provide specific support services. Data will be analyzed to measure possible differences 1) between mothers' and pediatric residents' responses, and 2) among responses given by PL-1's, PL-2's, and PL-3's.

COMMITTEE ON CLINICAL INVESTIGATIONS

Risks

There are no risks involved in this study. Participants simply answer questions, and all responses are treated confidentially. Respondents' names will never appear on questionnaires.

Benefits

Responses will be studied to learn how to improve the quality of health services provided to asthmatic children and their parents at Jacobi Hospital.

Results of the study may also indicate possible areas for further training related to parent-pediatrician communication which may be helpful to residents in the Department of Pediatrics.

	Yes	No
1. Will BMHC facilities be used for this project?	XX	
2. Will HAECOM facilities be used for this project?		XX
3. Will AECOM facilities be used for this project?		XX
4. Will there be any added expense to the Corporation in carrying out this project?		XX
5. Will there be any added expense to HAECOM in carrying out this project?		XX
6. Will there be any added expense to AECOM in carrying out this project?		XX

7. Referring to pages 4 and 5 of the instructions, I believe the attached research protocol

[ ] is exempt from Committee review [XX] is subject to expedited review [ ] needs Committee review

8. If the exempt or expedited box is checked, which numbered category (from page 4 and 5 of instructions) does this research fall into: #3 (research involving survey or interview procedures)

COMMITTEE ON CLINICAL INVESTIGATIONS

NEW DRUG OR DEVICE INFORMATION

(For proposals involving the administration of an Investigational New Drug or the use of a New Device)

"NOT APPLICABLE"

Name of Drug	
Manufacturer (Sponsor)	
IND or EID Number	Phase
1. Is FDA Form 1573 filed with manufacturer? ☐ Yes ☐ No	
2. Text of "Hold Harmless" letter from and signed by manufacturer: (If not applicable, state reason therefor. Please enclose a photocopy of the letter from the FDA that assigned the IND number, or a letter from the pharmaceutical company stating that they have been assigned an IND number and that it covers your proposed study.)	

COMMITTEE ON CLINICAL INVESTIGATIONS

APPROVALS

Signature, Principal Investigator	Date
[signature]	11/17/81

Participating Departments or Divisions:

Signature, Chairman, Primary Participating Dept.	Date
[signature]	11/16/81
Signatures of the following are required only where applicable	
Signature, Chairman/Director, Pathology N/A	Date
Signature, Chairman/Director, Laboratories N/A	Date
Signature, Chairman/Director, Radiology N/A	Date
Signature, Chairman/Director, Other Dept./Div. N/A	Date
	Date
	Date
	Date

Signature, Chairman, Committee on Clinical Investigations	Date
Signature, President, EMHC Medical Board	Date
Signature, Executive Director, EMHC	Date

PRIVACY FORM

As the Principal Investigator of research project -- "Quality of Support Services Provided to Parents of Asthmatic Children at BMHC as Perceived by Mothers and Pediatric Residents" --

to be carried out under the auspices of the Albert Einstein College of Medicine, I assume all responsibility for protection of the privacy of both control and test subjects, including being personally responsible if any information leading to a breach of that privacy is released by others. No published or unpublished report or visual or oral presentation of any aspect of this study will include any material that will permit identification of any individual subject to any person or agency other than to the named collaborators of this study.

11-17-81
Date

Ruth Stein
Principal Investigator

APPENDIX E

CONSENT FORMS SIGNED BY MOTHERS AND RESIDENTS

CCI NO. _____

ALBERT EINSTEIN COLLEGE OF EDUCATION - BRONX MUNICIPAL HOSPITAL CENTER
HOSPITAL OF THE ALBERT EINSTEIN COLLEGE OF MEDICINE

Individual's Consent for Participation
as a Subject in Clinical Research

By signing this form, I have agreed to participate as a subject in a medical research study entitled: "Quality of Support Services Provided to Parents of Asthmatic Children at BMHC as Perceived by Mothers and Pediatric Residents"

to be carried out under the supervision of the principal investigator

Ruth Stein, M.D.

Jacobi Hospital, 1300 Morris Park Avenue, Bronx, New York 10461
(Official Address)

212-430-5301.
(Telephone Number)

I have been told that I should be a patient in this study only if I want to, and that I may withdraw from the study at any time. I have also been told and assured that my treatment by, and relations with, the doctors and staff at the Albert Einstein College of Medicine (AECOM) and the Bronx Municipal Hospital Center (BMHC), now and in the future, will not be affected in any way if I refuse to participate or if I enter the program and withdraw later. Records of this study will be kept confidential with respect to any written or verbal reports making it impossible to identify you individually. If this research involves an experimental drug or device, there is a possibility that the U.S. Food and Drug Administration may inspect your record.

I understand that in the event of physical injury resulting directly from my participation in research at the AECOM and/or at BMHC, only immediate, essential, short-term medical treatment as determined by the doctors will be made available without charge to me personally for the injury and there will be no monetary compensation.

If this study is to be carried out at the BMHC, I have been told that I may seek further advice concerning this research project from the Patient Relations Office, Room 1S16, Jacobi Hospital (Telephone Number: 430-5181), Monday through Friday from 9:00 A.M. to 5:00 P.M. If this study is to be carried out at the Hospital of the AECOM, I have been told that I may seek further advice from the Patient Relations Office, Room 2-60, HAECOM (Telephone Number: 430-2395), Monday Through Friday from 9:00 A.M. to 5:00 P.M.

If any questions arise about injuries, reactions or any other matters that I believe may be related to this research project, I can call the principal investigator or Dr. Dorothy Jessop at Albert Einstein College of Medicine (430-8370). I have been given a copy of this form whether or not I have agreed to participate in this study. I have asked all the questions I want to ask, after reading and listening to an explanation of the four paragraphs on the next page, that are preceding my signature and describe:

1. The purpose of the research;

2. The procedures involved, any alternative procedures and duration of participation;

3. The risks that I will be taking, if any; and

4. The benefits that may result, to me or to others.

(MOTHERS' CONSENT FORM)

The purpose of this study is to evaluate the quality of support services provided to parents of asthmatic children treated at the Bronx Municipal Hospital Center. I understand that if I agree to participate in the study I will be interviewed one time only at Jacobi Hospital.

The procedure simply involves answering a set of questions. I also understand that all my answers are kept confidential, and that my child will not be interviewed at any time.

There are no risks or adverse reactions to be expected from participating in this study. I understand that during the interview I can refuse to answer any questions even though I have agreed to participate in the study.

The benefits that may result from being interviewed include helping to identify methods of improving the quality of health care for asthmatic children in hospitals, schools, and in their homes.

_____ _____

Witness

Signature
(Parent or Guardian, if necessary)

_____

Date

APPENDIX F

MOTHERS' QUESTIONNAIRE

MOTHERS' QUESTIONNAIRE

Interview Number: _____ _____

Date of Interview: _____ _____ _____
Day Month Year

Child's Age: _____ _____
Years Months

Child's Sex: Male 0
Female 1

Location of Interview: Ambulatory Care Clinic 0
Asthma Clinic 1
8th Floor Jacobi 2

Length of Interview: _____ _____
Hours Minutes

MOTHERS' QUESTIONNAIRE

(READ TO MOTHER):

I am a student at the University of Massachusetts in the School of Education. I am interviewing mothers of children who have been admitted to Jacobi Hospital to be treated for asthma. The interview takes about twenty minutes, and all your answers are kept confidential. Your name or your child's never appear anywhere on the form, and I do not show your answers to anyone.

During the interview, I will ask questions and mark down your answers. You will not be asked to fill out any forms. Mothers are interviewed one time only. Your answers will be studied to learn how to improve the quality of health services for children with asthma.

Before we begin, do you have any questions?

PART I: INTRODUCTION

(READ TO MOTHER):

The first part of the interview has some questions about your child's asthma and school.

1. In what grade is _____ at school?

   a. Kindergarten 0
   b. First 1
   c. Second 2
   d. Third 3
   e. Fourth 4
   f. Fifth 5
   g. Sixth 6

2. What kind of school does _____ attend this year?

   a. Public 0
   b. Parochial 1
   c. Private 2

3. Is Jacobi the only hospital you take _____ to for medical treatment for asthma?

   a. No 0
   b. Yes 1

4. How many times has _____ been hospitalized for asthma since the doctor first diagnosed the illness?

   _____ _____

5. Do other people in your family, not including your child with asthma, ask you for information about _____'s asthma?

   a. No 0
   b. Yes 1

6. If it is necessary, would you be able to keep asthma medicine at school?

   a. No 0
   b. Yes 1

7. Because of _____'s asthma, is it necessary to keep medicine at school?

a. No 0
b. Yes 1

PART II: INTRODUCTION

(READ TO MOTHER):

I am going to read a list of things that doctors sometimes do when they talk with mothers of asthmatic children. Your doctor may have done some of these things, and there are some items on the list that maybe you don't expect or need your doctor to do. Here are the possible ways that you can answer the questions. (HAND MOTHER "CARD A" AND READ EACH ITEM.) Please choose one answer for each question.

Answer Key:

1. My child's doctor has done this and I was very satisfied.
2. My child's doctor has done this and I was satisfied.
3. My child's doctor has done this and I was not satisfied.
4. I don't need or expect the doctor to do this.

(READ TO MOTHER):

Think back for a moment about times when you have talked with your child's doctor. If she/he has done this with you, how satisfied were you when the doctor . . .

1. Talked with you about things that worry you about _____'s asthma?	1	2	3	4
2. Encouraged you to call him/her when you have a problem or concern about _____'s asthma?	1	2	3	4
3. Reassured you when you became upset when talking about _____'s asthma?	1	2	3	4
4. Discussed specific problems or concerns you have about _____'s asthma?	1	2	3	4
5. Helped you think of other people, like friends or relatives, who could help you deal with problems caused by _____'s asthma?	1	2	3	4
6. Answered your questions about _____'s asthma?	1	2	3	4

7.	Explained how asthma will affect _____ in the next few years?	1	2	3	4
8.	Discussed how many months or years _____'s asthma is expected to last?	1	2	3	4
9.	Helped you think of other people who might need to know about _____'s asthma, like friends or relatives who live with you or spend a lot of time with _____?	1	2	3	4
10.	Gave you materials, like books or pamphlets, which explain how to take care of a child with asthma?	1	2	3	4
11.	Explained what to do if _____ has an asthmatic attack at home?	1	2	3	4
12.	Explained how _____'s asthma medicines help him/her?	1	2	3	4
13.	Explained how to give _____ asthma medicine?	1	2	3	4
14.	Talked with you about how well other people in your household can take care of _____ during an asthmatic attack?	1	2	3	4
15.	Explained how to control some things which might cause _____'s asthma attacks, like dust or certain foods?	1	2	3	4
16.	Talked with you about how often _____ has asthmatic attacks during the school day?	1	2	3	4
17.	Talked with you about keeping _____'s asthma medicines in school in case of an attack?	1	2	3	4
18.	Talked with you about how well _____'s teachers would be able to take care of _____ during an asthmatic attack?	1	2	3	4
19.	Discussed how asthma affects _____'s ability to learn and do school work?	1	2	3	4
20.	Talked with you about how asthma restricts _____'s physical activities at home, or in school gym classes and recess periods?	1	2	3	4

PART III: INTRODUCTION

(READ TO MOTHER):

There are many people at Jacobi Hospital who provide care for asthmatic children in the clinic and on the 8th floor. These people include doctors, nurses, nurse-practitioners, social workers, counselors, and psychologists.

I am going to read another list of things that these people sometimes do for mothers of children with asthma. I will ask you to tell me the person at the hospital whom you would most like to spend time with you doing these things. It doesn't matter who is doing it now, or who did it before. You can choose whomever you like from this list. (HAND MOTHER "CARD B" AND READ EACH ITEM.)

Again, you can also say that you don't need or expect some of these things from anyone at the hospital.

Answer Key:

1. General Pediatrician
2. Pediatric Nurse-Practitioner
3. Social Worker
4. Asthma Specialist
5. Nurse
6. Psychologist or Counselor
7. Other (Please Specify: _____)
8. I don't expect or need this service from anyone at the hospital.

(READ TO MOTHER):

Who at the hospital do you think should spend time with you . . .

1. Talking with you about things that worry you about _____'s asthma?	1	2	3	4	5	6	7	8
2. Encouraging you to call him/her when you have a problem or concern about _____'s asthma?	1	2	3	4	5	6	7	8
3. Reassuring you when you become upset when talking about _____'s asthma?	1	2	3	4	5	6	7	8
4. Discussing specific problems or concerns you have about _____'s asthma?	1	2	3	4	5	6	7	8

5.	Helping you think of other people, like friends or relatives, who could help you deal with problems caused by _____'s asthma?	1 2 3 4 5 6 7 8
6.	Answering your questions about _____'s asthma?	1 2 3 4 5 6 7 8
7.	Explaining how asthma will affect _____ in the next few years?	1 2 3 4 5 6 7 8
8.	Discussing how many months or years _____'s asthma is expected to last?	1 2 3 4 5 6 7 8
9.	Helping you think of other people who might need to know about _____'s asthma, like friends or relatives who live with you or spend a lot of time with _____?	1 2 3 4 5 6 7 8
10.	Giving you materials, like books or pamphlets, which explain how to take care of a child with asthma?	1 2 3 4 5 6 7 8
11.	Explaining what to do if _____ has an asthmatic attack at home?	1 2 3 4 5 6 7 8
12.	Explaining how _____'s asthma medicines help him/her?	1 2 3 4 5 6 7 8
13.	Explaining how to give _____ asthma medicine?	1 2 3 4 5 6 7 8
14.	Talking with you about how well other people in your household can take care of _____ during an asthmatic attack?	1 2 3 4 5 6 7 8
15.	Explaining how to control some things which might cause _____'s asthma attacks, like dust or certain foods?	1 2 3 4 5 6 7 8
16.	Talking with you about how often _____ has asthmatic attacks during the school day?	1 2 3 4 5 6 7 8
17.	Talking with you about keeping _____'s asthma medicines in school in case of an attack?	1 2 3 4 5 6 7 8

18.	Talking with you about how well _____'s teachers would be able to take care of _____ during an asthmatic attack?	1	2	3	4	5	6	7	8
19.	Discussing how asthma affects _____'s ability to learn and do school work?	1	2	3	4	5	6	7	8
20.	Talking with you about how asthma restricts _____'s physical activities at home, or in school gym classes and recess periods.	1	2	3	4	5	6	7	8

PART IV: INTRODUCTION

(READ TO MOTHER):

In the next section, I will read some statements that mothers have sometimes made when talking about their asthmatic children. After I read each statement, please tell me whether you "Agree" (0) or "Disagree" (1). (HAND MOTHER "CARD C.")

1. There is a full-time school nurse who is able to take care of _____ in case she/he has an asthmatic attack during the school day.

   a. Disagree 0
   b. Agree 1

2. _____'s teacher has called or written to me to ask about _____'s asthma.

   a. Disagree 0
   b. Agree 1

3. I am able to explain things about _____'s asthma to teachers who might ask.

   a. Disagree 0
   b. Agree 1

4. There are more things that I would like _____'s teachers to know about _____'s asthma.

   a. Disagree 0
   b. Agree 1

5. Sometimes _____ has problems in school because of asthma.

   a. Disagree 0
   b. Agree 1

6. Sometimes I wonder if _____'s teachers know everything they should about his/her asthma.

   a. Disagree 0
   b. Agree 1

7. Sometimes I worry that _____ will have an asthmatic attack at school.

   a. Disagree 0
   b. Agree 1

8. Teachers should ask me to tell them about _____'s health problems caused by asthma.

   a. Disagree 0
   b. Agree 1

9. The teachers at _____'s school are interested in hearing my concerns about his/her asthma.

   a. Disagree 0
   b. Agree 1

10. I should call or write to _____'s teachers to tell them what they need to know about his/her asthma.

   a. Disagree 0
   b. Agree 1

PART V: INTRODUCTION

(READ TO MOTHER):

This is the last part of the interview. I will ask some questions about you and your household. The reason that these questions are included is that there are about forty families in the study, and it is helpful to know how similar or different these families are in terms of how many people live in the household and other things. Again, none of your answers will be shown to anyone at the hospital or anywhere else. You may refuse to answer any of these questions.

1. How many people, including yourself, live in your household? _____

2. Are you . . .

   a. Married 0
   b. Divorced 1
   c. Separated 2
   d. Widowed 3
   e. Single (never married) 4

3. On what date were you born? _____ _____ _____
   Day Month Year

4. Which of the following comes closest to describing your family background? Do you consider yourself . . .

   a. Black 0
   b. Caucasian 1
   c. Hispanic 2
   d. Asiatic 3
   e. Other (Please Specify: _____) . . 4

5. Were you born in this country?

   a. No 0
   b. Yes 1

6. In addition to taking care of your family, do you now have a steady job outside the home?

   a. No 0
   b. Yes 1

7. How many years of schooling have you completed?

a. Never attended high school 0
b. Eighth grade or less 1
c. Some high school 2
d. High school graduate 3
e. Technical or business school after high school 4
f. Some college, 1-3 years 5
g. Finished college, 4 years or more 6
h. Other (Please Specify: _____) . . 7

8. What is the language you speak most often in your household?

a. English 0
b. Spanish 1
c. Italian 2
d. Other (Please Specify: _____) . . 3

9. During the past year, have you or anyone in your household received any income from . . .

a. Supplementary Security Income (SSI) 0
b. Social Security 1
c. Home Relief, Aid to Dependent Children (Welfare) 2
d. Unemployment Compensation 3
e. Pensions 4
f. Interest from Bank 5
g. Full-Time Employment 6
h. Part-Time Employment 7
i. Other (Please Specify: _____) . . 8

Thank you very much for answering all these questions. Is there anything you would like to add or ask me?

INTERVIEWER'S OBSERVATIONS

1. Respondent's verbal proficiency

    a. High (good vocabulary, little hesitation, elaborated with complex sentence structure . . . 1
    b. Medium (adequate for fluid communication) . . . 2
    c. Low (slow speech, loss for words, simple sentence structure) 3

2. Ability of respondent to understand the sense of the question

    a. Little understanding of most questions 1
    b. Moderate understanding of most questions 2
    c. Good understanding of most questions 3

3. Apparent ease of the respondent during the interview

    a. Relaxed throughout 1
    b. Became more relaxed during course of interview 2
    c. Became less at ease during course of interview 3
    d. Remained uneasy 4

4. Respondent's <u>overall</u> attitude toward the interview

    a. Friendly and eager 1
    b. Cooperative but not particularly eager 2
    c. Indifferent 3
    d. Hostile/Indifferent 4

MOTHERS' QUESTIONNAIRE

"CARD A"

1. My child's doctor has done this, and I was very satisfied.

2. My child's doctor has done this, and I was satisfied.

3. My child's doctor has done this, and I was not satisfied.

4. I don't expect or need the doctor to do this.

MOTHERS' QUESTIONNAIRE

"CARD B"

1. General Pediatrician: A doctor who treats all kinds of childhood illnesses, including asthma.

2. Pediatric Nurse-Practitioner: A nurse with special training who sees her/his own patients in the clinic.

3. Social Worker: A person who helps people with problems in their homes, in schools, or in the hospital. This person also sometimes makes referrals to other helping agencies, like Welfare or Social Security.

4. Asthma Specialist: A doctor who treats only children with asthma.

5. Nurse: A person who provides general health care to children in the clinic and on the 8th floor.

6. Psychologist or Counselor: A person who helps people by talking and listening.

7. Other (Please Specify): _____

8. I don't expect or need this service from anyone at the hospital.

MOTHERS' QUESTIONNAIRE

"CARD C"

1. Disagree

2. Agree

APPENDIX G

PEDIATRICIANS' QUESTIONNAIRE

PEDIATRICIANS' QUESTIONNAIRE

Interview Number: _____ _____

Date of Interview: _____ _____ _____
Day Month Year

Level of Training: PL-1 1
PL-2 2
PL-3 3

Length of Interview: _____ _____
Hours Minutes

PEDIATRICIANS' QUESTIONNAIRE

(READ TO RESIDENT):

I am a graduate student at the University of Massachusetts in Amherst. I am interviewing first-, second-, and third-year residents in the Department of Pediatrics about working with parents of asthmatic children.

The interview takes about twenty minutes. I will read questions and mark down your answers. You will never be asked to fill out any forms. All your answers are treated confidentially and will never be used for any form of evaluation. Your responses will be studied to improve the quality of health care for asthmatic children who are treated at Jacobi Hospital.

Before we begin, do you have any questions?

PART I: INTRODUCTION

(READ TO RESIDENT):

In the first part of this interview, I am going to read a list of things that some doctors do when they work with parents of children with asthma. The list, which has twenty items on it, contains things that you may or may not have done before with parents. Also, it is uncertain whether some of the items on the list should be done by doctors at all.

I am going to read each item and ask you to say how effective you have been if you have ever done these things with parents. You will need this list to answer each question. (HAND RESIDENT "CARD A" AND READ EACH ITEM.) Please choose only one response for each item.

Please understand that it is not expected that doctors will have done each thing, or that they have all been very effective in doing all the items listed. It may help you to know that in Part II you will be asked to talk more about items that you haven't done, or that you haven't been effective in doing. For example, one of the questions is about giving written materials about asthma to parents, and you may not have done this because the hospital doesn't have things like that to give to parents. The most important thing to remember is that you are not expected to be effective in everything mentioned on the list, and that there is usually a sound reason why people aren't as effective in some areas as they are in others.

Answer Key:

1. I have been very effective.
2. I have been effective.
3. I have not been effective.
4. I have never done this before.

(READ TO RESIDENT):

In general, how effective do you think you've been when you've spent time . . .

1. Talking with mothers about things that worry them about their child's asthma?	1	2	3	4
2. Encouraging mothers to call you when they have a problem or concern about their child's asthma?	1	2	3	4

3.	Reassuring mothers when they become upset when talking about their child's asthma?	1	2	3	4
4.	Discussing specific problems or concerns mothers have about their child's asthma?	1	2	3	4
5.	Helping mothers think of other people, like friends or relatives, who could help with them deal with problems caused by their child's asthma?	1	2	3	4
6.	Answering mothers' questions about their child's asthma?	1	2	3	4
7.	Explaining to mothers how asthma will affect their child in the next few years?	1	2	3	4
8.	Discussing with mothers how many months or years their child's asthma is expected to last?	1	2	3	4
9.	Helping mothers think of other people who might need to know about their child's asthma, like friends or relatives who live with them or spend a lot of time with their child?	1	2	3	4
10.	Giving mothers materials, like books or pamphlets, which explain how to take care of a child with asthma?	1	2	3	4
11.	Explaining to mothers what to do if their child has an asthmatic attack at home?	1	2	3	4
12.	Explaining to mothers how their child's asthma medicine helps him/her?	1	2	3	4
13.	Explaining to mothers how to give asthma medicine?	1	2	3	4
14.	Talking with mothers about how well other people in their household can take care of their child during an asthmatic attack?	1	2	3	4

15.	Explaining to mothers how to control certain things which might cause their child's asthmatic attacks, like dust or certain foods?	1	2	3	4
16.	Talking with mothers about how often their child has asthmatic attacks during the school day?	1	2	3	4
17.	Talking with mothers about keeping their child's asthma medicine in school in case of an asthmatic attack?	1	2	3	4
18.	Talking with mothers about how well their child's teachers would be able to take care of their child during an asthmatic attack?	1	2	3	4
19.	Discussing how asthma affects their child's ability to learn and do school work?	1	2	3	4
20.	Talking with mothers about how asthma restricts their child's physical activities at home, or in school gym classes and recess periods?	1	2	3	4

PART II: INTRODUCTION

(READ TO RESIDENT):

The next part of the interview contains the same list of items that you have already responded to. Some doctors, in a previous study, felt that although the list mentions services that mothers certainly need, people other than doctors should be doing these things.

I am going to read from the list again and ask you to specify the provider at the hospital whom you think is the most appropriate person to do these things for mothers. To answer these questions, you can refer to this list. (HAND RESIDENT "CARD B" AND READ EACH ITEM.) For some items you may think that only doctors should do those things, and in some cases you may believe that mothers should not expect these services from anyone at the hospital.

Answer Key:

1. General Pediatrician
2. Pediatric Nurse-Practitioner
3. Social Worker
4. Asthma Specialist
5. Nurse
6. Psychologist or Counselor
7. Other (Please Specify: _____)
8. Mothers should not expect this service from anyone at the hospital.

(READ TO RESIDENT):

The most appropriate person at the hospital to spend time _____ (INTERVIEWER READS EACH ITEM) is _____ (INTERVIEWER CODES RESPONSES FROM ABOVE LIST).

1. Talking with mothers about things that worry them about their child's asthma.	1 2 3 4 5 6 7 8
2. Encouraging mothers to call you when they have a problem or concern about their child's asthma.	1 2 3 4 5 6 7 8
3. Reassuring mothers when they become upset when talking about their child's asthma.	1 2 3 4 5 6 7 8
4. Discussing specific problems or concerns mothers have about their child's asthma.	1 2 3 4 5 6 7 8

5.	Helping mothers think of other people, like friends or relatives, who could help them deal with problems caused by their child's asthma.	1 2 3 4 5 6 7 8
6.	Answering mother's questions about their child's asthma.	1 2 3 4 5 6 7 8
7.	Explaining to mothers how asthma will affect their child in the next few years.	1 2 3 4 5 6 7 8
8.	Discussing with mothers how many months or years their child's asthma is expected to last.	1 2 3 4 5 6 7 8
9.	Helping mothers think of other people who might need to know about their child's asthma, like friends or relatives who live with them or spend a lot of time with their child.	1 2 3 4 5 6 7 8
10.	Giving mothers materials, like books or pamphlets, which explain how to take care of a child with asthma.	1 2 3 4 5 6 7 8
11.	Explaining to mothers what to do if their child has an asthmatic attack at home.	1 2 3 4 5 6 7 8
12.	Explaining to mothers how their child's asthma medicine helps him/her.	1 2 3 4 5 6 7 8
13.	Explaining to mothers how to give asthma medicine.	1 2 3 4 5 6 7 8
14.	Talking with mothers about how well other people in their household can take care of their child during an asthmatic attack.	1 2 3 4 5 6 7 8
15.	Explaining to mothers how to control certain things which might cause their child's asthmatic attacks, like dust or certain foods.	1 2 3 4 5 6 7 8

16.	Talking with mothers about how often their child has asthmatic attacks during the school day.	1 2 3 4 5 6 7 8
17.	Talking with mothers about keeping their child's asthma medicine in school in case of an asthmatic attack.	1 2 3 4 5 6 7 8
18.	Talking with mothers about how well their child's teachers would be able to take care of their child during an asthmatic attack.	1 2 3 4 5 6 7 8
19.	Discussing how asthma affects their child's ability to learn and to do school work.	1 2 3 4 5 6 7 8
20.	Talking with mothers about how asthma restricts their child's physical activities at home, or in school gym classes and recess periods.	1 2 3 4 5 6 7 8

PART III: INTRODUCTION

(READ TO RESIDENT):

In the next section, I will read some statements related to your general work with asthmatic children and their parents. Please choose one of these responses in answering each question. (HAND RESIDENT "CARD C" AND READ EACH ITEM.)

Answer Key:

1. Strongly Agree
2. Agree
3. Disagree
4. Strongly Disagree

(READ TO RESIDENT):

1.	In general, working with parents of asthmatic children is a satisfying experience for me.	1	2	3	4
2.	In general, I am competent in my work with parents of asthmatic children.	1	2	3	4
3.	In general, I think that parents of asthmatic children respond to me in a positive way.	1	2	3	4
4.	In general, working with asthmatic children is a satisfying experience for me.	1	2	3	4
5.	I would find it helpful to receive some training for communicating with parents of chronically ill children.	1	2	3	4
6.	Medical schools should provide elective parent-pediatrician communication training for students who are entering pediatric residencies.	1	2	3	4
7.	There are people in the Department of Pediatrics whom I can consult if I have a question about how to work with parents of asthmatic children.	1	2	3	4
8.	As a medical student, I received training for communicating with parents.	1	2	3	4

PART IV: INTRODUCTION

(READ TO RESIDENT):

This is the last part of the interview. I will be asking basic demographic questions. The reason that these questions are included is that it will be helpful to know how similar or different the total group of residents in the study are in terms of age, future plans, etc.

1. Sex: Male 0
   Female 1

2. Age in Years: _____ _____

3. Place of Birth: _____

4. Marital Status:
   a. Single 0
   b. Married 1
   c. Separated/Divorced 2
   d. Widowed 3

5. Do you have any children?

   a. No 0
   b. Yes . . . . . 1; PROBE: Number of Children: _____

6. In which region of the country did you complete the major part of your pre-college education?

   a. Northeast 0
   b. South 1
   c. Mid-West 2
   d. Far West and Rocky Mountains 3
   e. Foreign 4

7. Which medical school did you attend? _____

8. In which type of community do you wish to work?

a. Major large city 0
b. Suburb of major city 1
c. Small or medium-size city 2
d. Rural or farm community 3
e. Other (Please Specify: _____) . . 4

9. Which of the following comes closest to describing your family background? Do you consider yourself . . .

a. Black 0
b. Caucasian 1
c. Hispanic 2
d. Asiatic 3
e. Other (Please Specify: _____) . . 4

Thank you very much for answering all these questions. Is there anything you would like to add or ask me?

PEDIATRICIANS' QUESTIONNAIRE

"CARD A"

1. I have been very effective.

2. I have been effective.

3. I have not been effective.

4. I have never done this before.

PEDIATRICIANS' QUESTIONNAIRE

"CARD B"

1. General Pediatrician
2. Pediatric Nurse-Practitioner
3. Social Worker
4. Asthma Specialist
5. Nurse
6. Psychologist or Counselor
7. Other (Please Specify): _____
8. Mothers should not expect this service from anyone at the hospital.

PEDIATRICIANS' QUESTIONNAIRE

"CARD C"

1. Strongly Agree

2. Agree

3. Disagree

4. Strongly Disagree

APPENDIX H

LETTER TO RESIDENTS REQUESTING INTERVIEW

ALBERT EINSTEIN COLLEGE OF MEDICINE
OF YESHIVA UNIVERSITY
1300 MORRIS PARK AVENUE, BRONX, N Y 10461 • CABLE EINCOLLMED, N Y

November 18, 1981

Dear

I am a graduate student in the School of Education at the University of Massachusetts in Amherst. In a few days I will begin to collect data from pediatric residents and mothers of school-age asthmatic children who have been admitted to Jacobi Hospital.

The questionnaire, which I will administer during a twenty-minute interview, contains questions related to your attitudes toward and effectiveness with asthmatic children and their parents. The questionnaire will be completed during the interview and you will not be asked to fill out any forms.

All information collected during interviews will be treated confidentially and will not be used for any form of individual evaluation of residents. Your name will never appear on the questionnaire.

My schedule is very flexible and I will be available in the afternoons and evenings during the next few weeks. At the bottom of this page is a form which will tell me where and when I can find you for an interview. Please fill out the form and return it to me by Tuesday, 24 November 1981. There is an envelope with my name on it taped to the wall on the triage room in the Ambulatory Care Clinic.

I hope that you will be able to help by participating in the study. If you have any questions before you agree to be interviewed, please call me (Work Number: 430-8373 or Home Number: 822-4943), leave a note in the triage room envelope, or look for me in the Clinic.

Thank you very much.

Nadia Jensen

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